

2019 AbSPORU Studentship Award Recipients (11)

Christy Chong - University of Calgary

Project: *Understanding the perceptions of acute care service avoidability among patients with chronic kidney disease*



Biography

Christy is currently a first year Master's student in the Department of Community Health Sciences at the University of Calgary where she obtained her Bachelor of Science in Biological Sciences.

Her passion to improve patient outcomes for individual with kidney disease stems from her personal experience being a caregiver to her father, a recent kidney transplant recipient. During her undergraduate studies, she worked on a number of projects within the Nephrology Research Group.

This included examining trends in key quality of care indicators for patients with kidney failure, mobile application use for self-management in chronic kidney disease, and knowledge translation strategies for the dissemination of a clinical kidney pathway tool. Additionally, she worked with clinicians at the Alberta Children's Hospital to determine the optimal hemodialysis prescription for children with a rare metabolic condition and was involved in recruitment and surveying patients with kidney disease at the University of Alberta.

In her spare time, she loves learning about plants, baking pies and volunteering at the Rotary Flames House (a pediatric hospice) and the Kidney March. Christy is now translating her previous research, volunteer, and personal experiences towards her Master's degree. From her thesis, she aims to understand the perceptions of acute care avoidability among patients with kidney disease.

Project Summary

The number of individuals with chronic kidney disease (CKD) is increasing in Canada. Research has shown that patients with CKD are often heavy users of acute care services, such as the emergency department. Prior studies have found that patients often accessed

acute care services because they lacked home support, were physically and/or emotionally burdened by treatment, or valued the comfort received from medical professionals.

Having a strong, continuous relationship with a primary care provider has been found to be associated with greater quality of care, patient satisfaction, and overall health among patients with chronic disease. Understanding patient perceptions of potentially avoidable acute care use and how it is related to patient-provider relationships is an essential step in reducing unnecessary acute care use among patients with CKD.

Patients across Canada who have CKD have voiced the need for researchers to find ways to improve patient experience and health outcomes. Further, there is a need for acute care use avoidance strategies. Christy's project aims to champion these patient priorities by understanding the reasons that lead patients to access acute care services. It will explore these experiences to gain a broader understanding of why patients seek emergency care, whether continuity of primary care influences acute care use, and the extent to which this care was perceived as avoidable from the patient perspective. These findings will be used to create a foundation of knowledge that can reduce acute care use for potentially avoidable reasons, inform future interventions and improve patient outcomes and quality of life.

Adrijana D'Silva – University of Calgary

Project: Mind and yoga for Irritable Bowel Syndrome (MY-IBS) Study



Biography

Adrijana completed her undergraduate degree in Biological Sciences at the University of Calgary in 2011. Following graduation, she worked with the Alberta Inflammatory Bowel Disease Consortium as a Research Assistant.

She went on to pursue a Master of Health Studies at Athabasca University in 2017, focusing her thesis on physical activity, sedentary behavior, and health outcomes among lung cancer survivors. During this time, she also worked as a Research Associate for a lung cancer research group at the University of Calgary.

Currently Adrijana is a PhD student in the Faculty of Medicine, specializing in Health Services Research, Department of Community Health Sciences, and working under the supervision of Drs. Maitreyi Raman and Glenda MacQueen.

As an Irritable Bowel Syndrome (IBS) patient, she understands the challenges IBS patients face when they have a chronic condition without effective treatment. Her PhD aims to address this gap, through developing a series of patient-centered studies that she hopes will one day lead to the development of readily available and effective mind-body therapies for patients with chronic diseases. Using patient-oriented research, Adrijana's goal is to increase the involvement of patients in research to ensure their perspectives are included and their outcomes are improved.

Project Summary

Current evidence shows that yoga improves symptoms and quality of life and is safe in the treatment of IBS; however, more work is needed to determine if IBS patients and gastroenterologists are accepting of yoga as a therapy and how to best position yoga as a therapy for patients with IBS.

This research aims to determine if yoga is a beneficial and feasible therapy for patients with IBS. Adrijana will explore patient attitudes and preferences towards yoga interventions and methods of delivery (in person vs. online) so that yoga can be offered as a treatment option in a way that is acceptable to patients. Further, by creating a yoga program that considers patients' input, we expect that compliance with the program should increase.

This project will also determine how gastroenterologists feel about recommending yoga as a treatment option to patients with IBS and explore why they may or may not recommend this routinely.

Adrijana's research hopes to demonstrate that yoga is feasible by showing that we can recruit patients, and that is safe and has effect using endpoints that are important to patients such as improved symptoms. New knowledge in this field may provide a platform on which future treatments could be built. Advancing this field may also lead to increasing resources to support mind-body medicine.

Kelsey Ellis – University of Calgary

Project: *Exploring children, parent, healthcare providers and instructors' experiences with an individualized yoga intervention for hospitalized children receiving intensive treatments*



Biography

Kelsey is originally from Ottawa and completed her BSc in Human Kinetics at St Francis Xavier University. With a paid internship from the RBC Foundation, she accomplished her undergraduate honours thesis research examining the design and implementation of community-based aquatic programs for children with autism.

This study supported the sustainability and growth of evidence-based physical activity for diverse populations and inspired her to strive to continue to participate in patient-oriented research.

Her volunteer experiences have focused on physical activity provision for various marginalized populations who may not have access to community-based physical activity programs, including adults with intellectual disabilities, a child with Acute Lymphoblastic Leukemia, an aquatic rehabilitation intervention for an adult with a recently acquired physical disability, and cancer survivors and their support persons through the Thrive Center. Kelsey's volunteer and research experiences have contributed significantly to her interest in discovery in the field of integrative oncology.

Currently, Kelsey is a first-year MSc Student in Kinesiology at the University of Calgary, working under the supervision of Dr. Nicole Culos-Reed. She is an advocate for using exercise in the rehabilitation process as well to mitigate secondary conditions associated with cancer treatments and is looking forward to engaging in meaningful research through her graduate work that will aim to enhance the quality of life of cancer survivors by increasing physical activity provision.

Working with Dr. Culos-Reed and her team provides numerous opportunities for engagement in patient-oriented research, integrated knowledge translation, and a team environment that

supports collaboration and impactful research.

Project Summary

Yoga is a safe and feasible way to counteract many of the adverse effects faced by hospitalized children undergoing intensive treatments, including hematopoietic stem cell transplants (HSCT) and chemotherapy. Research has shown that yoga may help to reduce fatigue and improve quality of life for children hospitalized due to treatment. However, little is known about participants and families' experience in yoga, nor the perspective from either health care providers (HCPs) or yoga instructors.

This proposed research activity will use qualitative inquiry to explore childhood cancer in-patients and their caregivers' experiences within a randomized controlled trial (RCT) of a yoga/iPad intervention for fatigue. In addition, HCP and yoga instructor perspectives of yoga offered in-hospital for pediatric patients will be gathered. The larger multi-site RCT is comparing a 3-week individualized yoga program to an iPad control group for fatigue.

Participants are in-patients 8-18 years of age, receiving intensive chemotherapy for cancer or HSCT recipients who are expected to remain in hospital for at least 3 weeks, and their families. Interviews will be conducted with patients/families 2 weeks post-intervention and at 3-month follow-up; and with HCPs and yoga instructors at the end of the 12-month recruitment period. Interviews with patients/family will examine the yoga experience, barriers and facilitators, and whether they noticed any changes in health-related outcomes as a result of the intervention. HCP and yoga instructor interviews will examine the perceptions of the value of such a program, barriers and facilitators, beneficial features, and implications of yoga programs for future in-hospital practice.

Danielle Fox – University of Calgary

Project: *Urgent start peritoneal dialysis: The implementation of an enhanced program*

Biography



Danielle holds a Bachelor of Nursing Degree from the University of Lethbridge, as well as a Master of Nursing degree from the University of Calgary. Clinically she has worked as a registered nurse in various roles, most recently as a clinical nurse educator for the peritoneal dialysis and chronic kidney disease clinics in southern Alberta. She aspires to be a clinician scientist, driving innovative and impactful research questions based on her clinical work.

Currently Danielle is a doctoral student in the department of Community Health Sciences and proud to be a member of the Division of Nephrology with the privilege to learn from various research experts.

Danielle is passionate about conducting research that improves health care systems for patients and their families. Her research focuses on finding ways to best support people who manage complex care in home settings in hopes of creating both a positive and sustainable care experience. Her current research aims to improve care within this domain for people with kidney disease, however she hopes to expand her research to other care settings. She uses qualitative, quantitative and mixed methods in her work, and she looks forward to enhancing her skills in patient-oriented research through the Alberta SPOR Graduate Studentship.

Project Summary

One in ten Canadians have chronic kidney disease, which can lead to kidney failure. Hemodialysis (HD) and peritoneal dialysis (PD) are the two most common types of treatments for kidney failure and have similar patient outcomes. HD is most often done in hospitals or clinic and is very expensive. This has led to the promotion of PD, a largely home-based dialysis therapy which is significantly less costly to provide and has other benefits.

Many people need to start dialysis suddenly. Unfortunately, HD is the default way to start dialysis urgently because it is easier to get people on the therapy. This means that many people who choose PD do not get the type of dialysis they want. Urgent PD start programs are an option to overcome this problem but require a well-organized program. Urgent PD start programs are underutilized in Alberta even though they are successful elsewhere.

This research will improve the urgent PD start process by creating an effective program. The program will be created with input from patients and families, program administrators and front-line staff. This will ensure it meets the needs of its end users, giving people that want to do dialysis at home the ability and support to start successfully. The program will be started in Calgary, Alberta but will hope to be used in other areas in Canada if successful. This work will improve the care and health of Canadians living with kidney failure by getting them home on their therapy of choice as soon as possible.

Matheus Gonçalves Mussi – University of Alberta

Project: *User-centred design of brain-computer Interface systems for children with disabilities*



Biography

Matheus graduated in Control and Automation Engineering at the University of Caxias do Sul, Rio Grande do Sul, Brazil. With the help of data translation skills acquired in High School, he began an early research experience in his undergraduate program with an evaluation method in the area of electrical engineering.

His work with MatLab and statistical processing of data became his first academic writing and presentation, and received the ‘Metallurgist, Mechanical and Electrical Industry Syndicate’ Excell award at the ‘Young Researchers’ Encounter 2015. After which, Dr. Tairov and Matheus published the patent for their design.

Santander Bank of Brazil selected Matheus as one of the 100 students to receive the ‘Fórmula Santander’ Grant for International Studies. With that, Matheus completed an exchange experience the University ‘Politécnica de València’ in Spain where he attended one semester of engineering classes learning about other cultures and be more proficient in Spanish.

Working in the automobile industry as an intern at Agrale, he had the opportunity to build his technical and business skills in the Electrical Engineering department. He learned about product development, manufacturing, employee management and automobile assembly. As well, he worked with electrical wiring diagrams for trucks, buses, military vehicles and tractors.

As a research Fellow under the supervision of Marilda Spindola, their work on processing information from an electrooculography sensor worn by a patient with paraplegia to control an electric wheelchair received the ‘Metallurgist, Mechanical and Electrical Industry Syndicate,’ Prize at the ‘Young Researchers’ Encounter 2018. Matheus’s project moved to

Electroencephalography (EEG) signals and his thesis classified Motor Imagery signals from participants without disabilities.

The International Workshop on Assistive Technologies (IWAT 2019) accepted an article based on his thesis and research. Currently Matheus is pursuing a Master's degree at the Faculty of Rehabilitation Medicine which has led him to his current research project.

Project Summary

It is of interest of every child to be able to join groups of friends and play side-by-side with their peers. United Nations provided that all children have the right to play. Within this frame Matheus's research aim is to expand the abilities in children with disabilities using BCI systems that have the potential to benefit people with impairment in the areas of communication and leisure activities. The research attempts to develop a brain-computer interface system that can help individuals with severe physical impairments to execute tasks, such as turning lights on and off or playing a game with a pair.

Matheus's research considers several sessions to collect brain signals that can be processed by "smart computers" so children can play computer games or accomplish environmental control actions. For each child, the experimental setup will be tuned to maximize the system's effectiveness, tracking the children and parents overall experience to improve the process.

The research aims to generate a well-designed system so many children with disabilities can use it in their daily activities, verifying how it works for children, their experience with the technology and what technical/mathematical approaches are more likely to work.

Pamela Klassen – University of Alberta

Project: *Improving patient outcomes in non-small cell lung cancer with nutrient supplementation*



Biography

Pamela is a Registered Dietitian who completed her undergraduate degree at the University of Manitoba, graduating with the University Gold Medal and the Undergraduate Award in Dietetics from Dietitians of Canada. She subsequently worked in maternal health, transitioned to diabetes education and finally, practiced in oncology nutrition at Cancer Care Manitoba.

Through supporting patients during cancer treatment, she recognized the need for new research and evidence to benefit this population who are vulnerable to malnutrition, wasting and long-term side effects of treatment. With encouragement from her colleagues and employer, she moved with her family to Alberta to pursue graduate studies with a focus on nutrition and metabolism in cancer.

Currently, Pamela is a Master's student in Nutrition and Metabolism in the Department of Agricultural, Food and Nutritional Sciences. She is passionate about doing research that informs clinical practice to improve patient outcomes. Her Master's degree is possible due to the strong partnership between the Department of Oncology within the Cross Cancer Institute and her supervisor at the University of Alberta, along with the patients who are willing to participate in clinical research for the benefit of others.

Project Summary

Lung cancer is the leading cause of cancer-related death in Canada and is most often diagnosed at an incurable stage. Chemotherapy is given to keep the tumours from growing, lessen symptoms and provide longer life.

Recently, the addition of immunotherapy has been found to improve survival in a portion of patients. Chemotherapy and immunotherapy, however, can have difficult side effects for

many patients, sometimes resulting in fewer treatments.

Quality of life and ability to function, which are extremely important to patients, are also frequently impacted by lung cancer and chemotherapy. Many patients experience severe muscle loss, which limits their ability to do the activities they enjoy and recover from each treatment. Often patients express the feeling of 'living in someone else's body' because their body change is so profound, even when they continue to eat normally.

A nutritional supplement has been shown in previous studies to protect patients from treatment side effects while also improving the benefit of chemotherapy. This same supplement can slow or stop muscle loss in cancer patients, improving their daily function and quality of life.

These results have been found in small studies; therefore larger, well-designed studies are required so that the results can be confirmed and translated to a clinical practice setting. Pamela's research study at the Cross Cancer Institute aims to confirm whether this nutrient supplement, along with chemotherapy or immunotherapy, can improve the benefit of treatment while preserving muscle and function for patients.

Alyson Kwok – University of Alberta

Project: *Maximizing patient engagement through collaborative outcome measure selection and tracking: patients' perceptions of the use of physical therapy outcome measures post-stroke*



Biography

Alyson graduated with a BScPT from the University of Alberta in 2004 and has worked as a Physical Therapist in Edmonton for the last 15 years, primarily treating patients who have had a stroke in both acute and subacute settings.

She spent several years as the team leader of the Stroke Physical Therapy team at the Glenrose Rehabilitation Hospital, working to ensure clinicians had access to best practice information through initiatives such as a provincial stroke PT Community of Practice.

Currently, Alyson is part of the Healthcare Improvement Team at the Glenrose, where she assists and leads projects focused on quality improvement, evaluation, research and implementation of best practices. In addition to her clinical work, she has remained connected with the University of Alberta as an instructor of both the lab component of the Adult Neurology MPT labs and the Neurology module of the Graduate Bridging Certificate Program.

As an instructor, Alyson works to bridge the gap between student and clinician, bringing real-world examples and case studies into her teaching. Her efforts have been rewarded with both a RMSA Excellence in Teaching award and a Graduate Student Assistance Teaching Award.

Alyson has spent years working directly with patients and has become passionate about ensuring the patient voice is incorporated at every level of healthcare. She is now exploring patient engagement and outcome measures with Dr. Trish Manns in the Faculty of Rehabilitation Medicine.

Project Summary

After a person has had a stroke, they often receive physical therapy to improve their mobility. Physical therapists regularly measure a patient's progress using standardized outcome measures, such as timing how quickly a person can walk. Currently in Alberta, the way in which these measures are selected is not standardized, so a person may not receive the same type of tests as they move to different facilities or therapists. Patients may not fully understand which outcome measures are selected or how the measures track progress towards their health goals. This project will involve talking to people who have received physical therapy after stroke in group interviews, called focus groups. The information gathered will help us to better understand what outcome measures are meaningful to patients and how they would like to be involved in tracking their own progress.

The whole project will be guided by a small research team, which will include one to three patient advisors. Patient advisors are former patients who have relevant personal experience and contribute their perspective to the study. Patient advisors help to keep the research team focused on the patient experience.

The end result of this project will be a set of recommendations regarding how patients and therapists can collaborate to select and track outcome measures in a way that resonates with patients who receive physical therapy after stroke. If put in place, these recommendations could help patients to actively participate in their own care by monitoring progress toward their stated goals.

Ryan Mallard – University of Calgary

Project: *Working with communities to bring healthcare and social services to places where it's needed the most*



Biography

Ryan completed his bachelor's and master's degree in psychology at the University of Lethbridge. Since then, he has worked as a research associate on an international research project trying to increase access to primary health care for people who are underserved by, and struggle to connect with primary health care services.

Within his vast experience, Ryan has worked in the healthcare system, where he was a business analyst. Also, he has worked with minority populations such as people with schizophrenia, newcomers to Canada, and LBTTQ+ people which has greatly influenced his research priorities and community work as a PhD student in Community Health Sciences.

Ryan is also an acrobatics and gymnastics coach and is passionate about teaching and watching his students learn and grow.

Project Summary

Many communities or certain areas of communities are underserved by health and social services. If someone lives in an underserved region of a community, accessing health and social services may be more difficult. Accessing services may be especially difficult for people with fewer resources, lack of supports, and limited ability to navigate the health and social services system. A pop-up model of service delivery brings multiple health and social services to where people need them the most.

This “one-stop-shop” approach gives people the opportunity to access multiple services without having to navigate the often-difficult health and social services systems. These events “pop-up” in easy-to-reach locations where people are already gathered (e.g., schools and seniors' centres) and provide services to anyone wanting them. The pop-up model also stresses the importance of service providers working together to provide care, making



meaningful connections with people, and creating a welcoming and engaging environment for all.

The pop-up events were successful in Lethbridge, Alberta, with both service providers and people accessing services praising the feel of the pop-ups, as well as this new approach to service delivery.

Not surprisingly, the pop-up model has gained national and international interest. However, how local factors influence the success of the pop-up model in different communities are not known. Ryan's research therefore hopes to understand how local factors influence the pop-up model when used elsewhere, while also providing "lessons learned" from the successful pop-ups in Lethbridge, Alberta.

Anika Sehgal – University of Calgary

Project: *Complexity among Indigenous patients: Developing and validating a clinical assessment tool to address the broader determinants of health*



Biography

Anika completed a Master's degree in Industrial and Organizational Psychology where she examined barriers to employment, workplace experiences, and causes of turnover in the workforce among Indigenous populations, grounded on Call 92 which engaged Canada's corporate sector.

Her findings determined that one of the primary reasons behind the employment inequity was due to Indigenous peoples having limited access to healthcare and greater health problems, preventing them from obtaining and retaining employment. Based on this, she was inspired to change career paths and pursue research aimed at improving both health outcomes and healthcare access for Indigenous peoples.

Currently Anika is a PhD candidate in the Department of Community Health Sciences, specializing in Health Services Research. Based on the Truth and Reconciliation Commission's Final Report, her research aims to address the health legacy Calls to Action through promoting health equity and transformations in current frameworks of healthcare.

Project Summary

Indigenous peoples in Canada continue to have overall poorer health than their non-Indigenous counterparts. This discrepancy in health status can be linked back to the social determinants of health, such as income, social status, and physical environments, rooted in the legacy of ongoing colonialism. As such, disease complexity among Indigenous patients can often arise from factors that may not be directly related to health, but still play a role in their disease outcomes. Therefore, the purpose of Anika 's study is to develop an assessment tool that can be used by healthcare providers to better understand the physical, social, and psychological factors that play a role in the health of Indigenous patients.

Current tools that are used to assess patient complexity are unable to consider factors unique to Indigenous patients such as intergenerational trauma, perpetual racism, and historical loss. This tool will be centred on the lived experiences of Indigenous peoples and will be used to better inform healthcare providers regarding the impact of the broader determinants of health and how they shape health outcomes.

By using a tool developed with Indigenous patients, for Indigenous patients, current systems of healthcare can be decolonized to improve both access and care, and in turn, improve patient outcomes. Consistent with the guidelines of the TRC which described reconciliation as “an ongoing process of establishing and maintaining respectful relationships,” this research rests on developing sustainable relationships with Indigenous patients to close current gaps in health equity.

Trina Thorne – University of Alberta

Project: *Developing a trauma informed intervention to reduce responsive behaviours in persons with moderate to severe dementia.*



Biography

Trina has been a registered nurse in Edmonton for over 17 years. After completing her MN - Nurse Practitioner (NP) program at the University of Alberta in 2014, she began working as an NP in a variety of Continuing Care settings.

Trina started her PhD program in 2019. Her research aim is to develop interventions that will improve the experience of both providing and receiving care in long-term care settings. Her nursing background helps her understand the factors that affect best practice implementation and how individuals with dementia experience the health system.

Project Summary

Past trauma exposure is common and under-assessed. Psychological trauma can result in devastating health outcomes such as post-traumatic stress, depression, anxiety, cognitive dysfunction, chronic disease and premature death. Exposure to traumatic events alters both brain function and structure, affecting responses to stress. Undetected histories of trauma for people living in long-term care (LTC) settings can create major problems for both residents and caregivers. Even when a history of trauma is known, frontline staff have little guidance on effective strategies to manage the consequences of psychological trauma.

In LTC, residents can experience numerous trauma-related stimuli or triggers that elicit exaggerated behavioural responses as reactions to fear, disempowerment and loss of control. A common trigger is bathing and intimate hygiene, which may be interpreted as danger by the reactive areas of the brain (lower regions), eliciting emotional, physiological and behavioural responses for survival and safety. These responses are rarely treated appropriately as care providers do not understand the origin or how to use trauma-informed strategies based on neuroscience to limit the reaction. Thus, preventive strategies are rarely

employed.

Although specific sub-groups are known to experience severe trauma responses in LTC (veterans, holocaust survivors), few studies have evaluated the impact of past trauma or stress injury on behaviour in residents with moderate to severe dementia.

No studies in LTC have specifically evaluated outcomes of trauma-informed, neuroscience-based interventions. Trina's research will provide an empirical foundation for interventions with the potential to reduce emotional and psychological symptoms as well as aggressive behavioural responses to trauma triggers.

Billy Wang – University of Alberta

Project: *Implementation and evaluation of novel patient-centered initiatives in a multidisciplinary Heart Function Clinic*



Biography

Billy began his MSc in Medicine at the University of Alberta following the completion of his BSc honors degree in Physiology. His undergraduate experience is enriched by the broad scope of research activities he was exposed to encompassing both basic and clinical research. He joined Dr. Oudit's group during his undergraduate thesis investigating the prognostic value of Renin-angiotensin system biomarkers in heart failure patients.

These experiences provided him incredible opportunities to work directly in outpatient and acute inpatient care settings, from which he developed a passion for patient-oriented research. Originally from Calgary, Billy enjoys hiking, kayaking and skiing in the mountains and is often found planning for his next travelling destination.

For his Master's thesis, he will participate in the Heart Function Clinic at the Mazankowski Alberta Heart Institute, which utilizes a multidisciplinary care model, consisting of cardiologists, nurses, pharmacists, dieticians and geneticists centred around patients and their caregivers. Through empowering patients to participate in the implementation of novel patient-oriented initiatives to integrative supportive care and genetic consultation into routine clinical practice, Billy will assist in developing and evaluating an approach for future referrals that is guided by patient-identified priorities.

He hopes to develop his capacity to conduct patient-oriented research by seeking new ways to engage patients and learning methodologies to evaluate healthcare initiatives. Ultimately, Billy hopes to better understand patient experiences for those suffering from heart failure and intends to use his investigations to augment the patient care process for improved outcomes.

Project Summary

Over 600,000 Canadians are suffering from heart failure (HF), with 50,000 new diagnoses

each year, causing an enormous burden on patients and our healthcare system. Medical treatment for HF has seen remarkable advancements over the past several decades. However, there is presently no cure for HF, and despite optimal medical therapy, patients continue to deteriorate in waves, with initial recovery from medication changes followed by rapid deterioration, leaving patients disheartened and causing enormous stress for HF caregivers.

At our multidisciplinary Heart Function Clinic (HFC), we are beginning to implement two novel patient-centered initiatives to integrate supportive care and genetic consultation into routine clinical practice for advanced HF patients to reduce stressors and improve their quality of life. However, before these initiatives can become incorporated into routine clinical practice, several key factors including identification of patients in need, timing of referrals, efficiency and efficacy of these initiatives require further investigation.

A longitudinal design will be utilized for the study. Where demographics, etiology, diagnostics and management plans of patients frequently visiting the clinic will be collected with patient's informed consent. In-person interviews will be conducted with patients to assess the impact of HF on the quality of life, which will initially be used to optimize the patient identification and referral process. Referred patients will be subsequently followed for 5 years with repeated evaluations at the 1,3- and 5-year mark. Findings from Billy's study will help shape future guidelines on the management of advanced HF patients by implementation patient-centered initiatives in the HFCs.