Annual Report
2018

THE KER UNIT
Knowledge and Evaluation Research Unit
Mayo Clinic, Rochester, Minnesota

A Family Affair
Overview

The KER Unit is a family. This was the conclusion of our strategic retreat in early 2018. Rather than relationships of blood, our family is bound by principles: patient-centeredness, integrity, and generosity. From this perspective, the annual report you are reading might just as well be a holiday greetings letter celebrating the accomplishments of several members of our family. Prominently absent are the tens of colleagues – from trainees to faculty – who grew with the unit, grew the unit, and outgrew it. For many, the KER Unit has been a safe community in which to explore questions of professional identity, to learn by doing with the impostor syndrome at bay, and to celebrate our accomplishments, which like our work, are always achievements of this community. Of this family.

Beyond the metrics, which are themselves a testimony of the productive work that takes place collaboratively in our unit, our biggest celebrations always arise from the stories we are able to tell of the impact of our work on others, particularly on patients and clinicians anywhere. True, the value of our research arises from the elegance of the methods, the rigor of the analyses, and the clarity of the reports. As beautiful as our work may be, what gives it its worth is the possibility that it can help someone to make a better decision, to make someone better, or to feel better.

Our visitors always remark on the environment of camaraderie, mutual support, and fun that our family keeps. Every October we receive them from all over the world during our Workshop and we roll our sleeves to learn together how to make the world better through research. I hope that in reading these pages you will get the feeling they get when they spend a few days with us.

And here it is. Offered with humility and excitement. From our family to yours.

— VICTOR MONTORI

Milestones

Take a look at some of our family’s milestones for 2018.

Covering topics such as...

- Listening in delicate clinical encounters
- Diagnostic reconciliation
- Cost in healthcare discussions
- Care planning in advanced kidney disease
- Atrial fibrillation
- Acne
- Osteoporosis
- Thyroid cancer
- Burden of treatment for dialysis patients
- Goals of care for the frail elderly
- Undercared-for chronic suffering
- ...and more!
This year the KER Unit teamed up with Morrison Health Care to participate in the Boys and Girls Club Chili Challenge. Our theme was “Lions and Tigers and Chili Oh My!” With help from many people, we were able to win the Spicy Spirit Award for the 10th year in a row. We were also awarded the Cash Cow prize for raising the most cash for the Boys and Girls Club.

Many thanks to Joy Robison and Ian Hargraves whose hard work was a major contributor to the visuals of our tent. Thanks also to the spirit of Claudia Tabini and Victor Montori who dressed up as a parrot and gorilla. Finally, we would like to extend a big thank you to Morrison Health Care for their delicious chili!

Top: Paige Organick, Claudia Tabini, and Victor Montori pose in front of the KER Unit tent.
Bottom: Anjali Thota and Aaron Leppin monkey around.

CONGRATULATIONS, ORGANICK-LEE!

John Lee and Paige Organick got engaged in October 2018 while hiking in Iceland.

John is a medical student at the Mayo Clinic and Paige is a Clinical Research Assistant at the KER Unit.

They live with their dog, Pippin and cat, Ollie.
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SAVE THE DATE
OCTOBER 7-9, 2019
Beginning in 2019, our annual Minimally Disruptive Medicine workshop will now be known as Care That Fits!
10/7-8 | Main Course
10/9 | Capacity Coaching Intensive
Register
https://ce.mayo.edu/family-medicine/content/care-fits-2019

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Sarah McCarthy is an Assistant Professor of Psychology. Prior to joining the staff at Mayo Clinic, she was a faculty member at Harvard Medical School and an attending psychologist at Dana-Farber Cancer Institute and Boston Children’s Hospital. She received her undergraduate degree in psychology from Connecticut College, her doctorate from Emory University, and her masters in public health from Harvard University. She was Pediatric Health Services Research fellow and a fellow at the Institute for Healthcare Improvement. Dr. McCarthy’s research focuses on: 1) understanding the challenges patients and families experience in healthcare communication and decision making; 2) engagement of the pediatric patient in healthcare communication and decision making, and 3) the development of appropriate interventions to address identified barriers.

As evidence of her high level of research accomplishments, Dr. McCarthy has 24 peer-reviewed publications, nine of which are first-authored, in highly regarded scientific journals such as Journal of Oncology Practice, Psycho-Oncology, and Pediatric Blood and Cancer. In addition, she has written four book chapters, one of which was first-authored. Dr. McCarthy has established a national reputation through numerous invited, oral, and poster presentations including presentations at the 2016 National Conference on Pediatric Psychology, the Seventh Annual Conference on Pediatric Sleep Medicine, and the 2017 National Society of Genetic Counselors.

Christina is a qualitative research fellow and has been thrilled to call the KER Unit her academic home for the better part of this past year. Before coming to Rochester with her husband Inuk Zandvakili, who’s an internal medicine resident, she spent 7 years at the University of Cincinnati completing her M.A. and Ph.D., specializing in rhetoric and composition. She finds the interdisciplinary collaboration in KER incredibly rewarding, and she is grateful it has allowed her to examine the rhetorics of patients’ social experiences with illness, navigating their care, and communicating with clinicians. She also brings her expertise in theories of writing and writing pedagogy to mentoring others in writing, as well as teaching a Scientific Writing workshop series for the Office of Postdoctoral Affairs.

Outside of work, Christina enjoys cooking (her specialty is pizza made from scratch), yoga, biking on Rochester’s many trails, swimming, playing violin (she double-majored in music and English in college), and spending time with Inuk.
I have had the rare opportunity to be part of the KER Unit family since January 2018. Since my first day at Mayo Clinic, as Research Trainee, I felt how each member of this group has a true interest in learning, teaching, and sharing everything. One of Victor’s sayings perfectly defines the KER Unit experience: “In this place you can do whatever you want to do. You can be part of the current projects or you can create your own projects, all is up to you. You will learn as much as you are willing to, the only limit is yourself”.

During my time at the KER Unit I learned so many things that it would be impossible to list all of them here, but I would like to summarize my learning in three big fields: teamwork, evidence-based medicine and patient-centered care.

I became a Research Collaborator, and I still work on projects with almost everyone in the unit. The work moves forward so easily that now working alone is relatively impossible. Evidence-based medicine, and specifically meta-analysis and systematic reviews, was the majority of what I learned in the unit, and I had the opportunity of being part of at least ten of them, to the point I feel ready to be the head of new projects by myself. One important thing I learned about is patient-centered care, a huge field and regrettably under-known for several clinicians and researchers. JP helped me understand this area with these words: “When you think in a research idea, the most important question should be: How is this important for my patients? Because in the current research world “statistical significance” is the base, but is it what really matters to our patients?”. I close this text hoping that more people have the opportunity to be part of the KER Unit and get to know each incredible member of this family. Thanks to the KER family for this great experience!
Francisco Barrera

Short, deep, and intense are the three words that best describe my experience in KER unit. I learned a lot from each and every one of the incredible members of this family. Everybody loves to work and I love that. The work environment is at its finest. They made me feel at home since the very beginning. One of the best lessons I take home is that when JP (“yeipi”) and I were talking about a research project, and he told me: “Just remember that the results from every research must mark the beginning of another one and most contribute to the greater picture; every research project is bounded to the next one, and most contribute to improving the patient care”.

Throughout my stay here, I got involved in as many projects as I could. But most importantly, I had the support to develop a few of my own. I worked on a systematic review to assess the effectiveness of interventions made to foster cost conversations between patients and clinicians. I had the opportunity to start this review from the beginning and even to lead the project. Cost discussions are considered a key element for high quality care. Surprisingly, we found out that there is a huge lack of interventions to foster them!

Research has become a great passion in my life. It has changed my way of thinking, acting, and approaching and resolving problems. It’s awesome and very satisfactory the fact that you can generate knowledge through research. But it is even more when you know that your work is contributing to a bigger purpose: to get closer to the type of care that every patient deserves.

Natalia Genere

I have had the pleasure of being part of the KER unit from July 2018 – June 2019, during the research year of my clinical Endocrinology fellowship at Mayo Clinic. Both Drs. Montori and Brito have taken me under their wing, and helped me to develop my own research interests and to find my place in the field of Endocrinology. Furthermore, everyone in the unit is extremely kind and passionate about their job, which makes the KER unit consistently a positive and inviting place to be.

So far this year, I have focused on understanding clinician decision making in diagnosis and management of high-suspicion thyroid nodules and thyroid cancer. We are accomplishing this by using a variety of methodologies, including epidemiologic studies, historical cohorts and retrospective studies. Other studies of interest have involved survey studies and validation studies for adrenal diseases, and for other non-cancerous thyroid conditions.

In the KER unit, there are at least two weekly opportunities to hear about projects of our researchers or associated groups. This allows all members to be exposed to a breadth of methodologies, interests, and career goals, which, I believe, bolsters individual creativity. There is also an opportunity for immediate feedback on projects with challenges in planning or execution. In my own research, I have found the KER patient advisory panel quite insightful in making sure that patient-important outcomes are included in study design, and in developing possible QI projects within the division of Endocrinology.

Thank you, KER unit, for the excellent experiences and collaborations! Looking forward to the rest of the year!
In 2018, Kasey Boehmer defended her dissertation, “Minimally Disruptive Medicine; State of the Science and Plan for the Future.” In this three-paper dissertation, Kasey sought to 1) conduct a systematic review and synthesis of recent interventions using the Chronic Care Model to examine the extent to which MDM had been adopted within those interventions; 2) evaluate the implementation process of a six-month pilot of an MDM-driven intervention, Capacity Coaching, in primary care using focused ethnographic observations and in-depth interviews; and 3) propose a detailed protocol to implement and test MDM using a proven culture-change curriculum.

She found that CCM implementations examined were mostly aligned with the healthcare system’s goals, condition-specific, and targeted disease-specific outcomes or healthcare utilization. No CCM implementation addressed patient work. Few reduced treatment workload without adding additional tasks. Implementations supported patient capacity by offering information, but rarely offered practical resources (e.g., financial assistance, transportation), helped patients reframe their biography with chronic illness, or assisted them in engaging with a supportive social network. Capacity Coaching’s implementation, however, addressed most of these shortcomings of past chronic care interventions, including being available to patients living with any chronic condition(s), acknowledging and seeking to reduce patient work, and supporting patient capacity holistically across all constructs described in the Theory of Patient Capacity. Its implementation was successful in getting many individuals on the healthcare team to understand the purpose of the program and the ways in which it was distinguishable from other programs and in getting a small group of dedicated champions to drive implementation of the program forward. However, implementation struggled to get a broader group of individuals across the clinic involved in the program and to build in evaluation of the program’s success. These challenges are ones specifically addressed in the Leadership Saves Lives culture-change curriculum. Kasey has published the first paper of the dissertation in PLoS One, and she intends to publish the second paper in 2019.

Most importantly, Kasey would like to thank with tremendous love the KER Unit and the broader network of KER supporters for their unwavering support in finishing her PhD, a dream of which the foundation was first laid after she began at KER seven years ago. Without the energy of her environment and social network, her capacity to achieve such feats might not have fully been realized.
Finding doctors to work and stay at another clinic we went to was challenging. With a lack of physicians wanting to stay in rural clinics, the administration had to make the difficult decision of closing the only clinic in the area. We heard story after story from patients struggling with not knowing what to do for their healthcare, and physicians feeling immense guilt for leaving people they have been charged with caring for. We struggled watching this, helpless and hapless researchers on the sidelines.

ICAN gave us the ability to see why rural healthcare is such a widespread area of health disparity. Firsthand, we saw the struggles clinics, clinicians, and patients face. With these experiences, our ideas of what we want for our future careers have changed. Paige now hopes to go into public health to address healthcare disparities and provide interventions to change the world of healthcare. While Anjali has always hoped to become a physician, working in research and understanding access issues in healthcare has altered her understanding of what being a “good doctor” means.
Aaron Leppin

2018 was a fruitful year in regards to efforts around dissemination and implementation. It’s been exciting to see the role our small team has played in increasing institutional awareness and capacity in this space. Specifically, the Dissemination and Implementation Methods Working Interest (DIMwits) Group has grown to include more than 15 active members from disciplines ranging from nursing to pharmacy to clinical medicine and diverse backgrounds in research. To supplement educational activities occurring within the monthly DIMwits meetings, a small group attended the D&I short course in Madison, Wisconsin. Here we learned about the relationship between D&I and health disparities research. Our group was also benefited by a visit and grand round presentation from Dr. Carl May, an internationally-renowned expert. As a sign of institutional interest in D&I, the Kern Center has chosen the topic as the educational theme for 2019.

Related to this, the DIMwits are busy developing Mayo’s first official curriculum in D&I. We anticipate this will be finalized in Fall of 2019. In service to the institution, our D&I consultation office has advised on projects and grant submissions at a rate of about 2-4/month. Currently, we are involved in 12 externally funded implementation research grants and are involved in countless more submissions. In an effort to increase our external visibility and service, we have been actively participating in the Dissemination, Implementation, and Knowledge Transfer Workgroup of the CTSA Consortium. This has resulted in a manuscript in the final stages of preparation. Lastly, in recognition of our methods for the WellConnect project, we won the Great CTSA Team Science Competition. Clearly, 2018 was a momentous year, but 2019 shows no signs of slowing.

Maggie Breslin

The Patient Revolution

This year has seen substantial progress in the scope and number of projects The Patient Revolution has taken on. This includes work with Mayo Clinic Health System (co-creating new approaches to access with the clinic and community), Cincinnati Children’s Hospital (a communication tool for families and pediatricians for kids with ADHD) and some innovative projects with Yale (community events to support shared decision making for mammography screening and CV risk). These projects are vitally important as they help put our ideals into action, and also serve as examples to generate awareness of the mission with our growing audiences.

Victor’s book, ‘Why We Revolt’ continues to command attention. The book provides examples of where health care fails due to greed, cruelty, the burden of care, and the “blurry” patients that the system creates. By illustrating an alternative concept based on love, solidarity, elegance, and integrity, people now have the language to describe why health care needs to change. Victor has traveled extensively and has been able to present these topics to an expanding global audience.

We have also expanded our footprint online, participating in podcasts and running tweet chats which recently took a chapter of our book as a core theme and asked the online community to join us in discussion. Kerri Sparling has been leading this excellent work which has included an expansion of our story library on our website.

As we turn towards 2019, The Patient Revolution is focused on increasing the scope of our program work in the form of a ‘school’ in which we teach participants – patients, caregivers, clinicians - how they can bring about careful and kind care through their own actions. Our first class ‘Shared Decision Making for Everyone’ will launch in Feb/March. patientrevolution.org.
Researchers from Arizona State University’s School for the Science of Health Care Delivery and the KER Unit at Mayo Clinic are pursuing collaborative research on the burden of work of dialysis patients, the impacts of this burden of work on patients’ lives, and the practices through which patients navigate the healthcare system to coordinate treatment. By utilizing a mixed-methods, explanatory sequential study of patients drawn from two dialysis clinics, this research will produce a deep qualitative understanding of these patients’ everyday strategies for coordinating their care within the complex and fragmented healthcare delivery system, which will in turn inform design, deployment, and evaluation of an intervention to improve clinical care delivery and illness management for dialysis patients.

Patient surveys were administered at both Eisenberg and Northeast dialysis centers which assessed the type and degree to which patients experience treatment burden using the Illness Intrusiveness Scale. Participants that scored most and least burdened by illness from the survey data were reached out to be interviewed (32) and observed (4). Participants were asked a series of open ended questions regarding their treatment burden and day-to-day life as a dialysis patient.

Analysis will include researchers looking at data and compare identified themes or patterns found in patients both ranked with least and most burden, then compare the differences. The team hopes to find where and how participants experience treatment burden and what resources (e.g., skills, networks, tools) participants use to cope with treatment burden. Additionally, to our initial objective to examine the patient and healthcare practices associated with varying levels of treatment burden and publish our findings, we also aim to design an intervention to minimize treatment burden related to dialysis and increase patient capacity to cope with burden of dialysis treatment, resulting in a grant proposal for a larger funding body.
Marleen Kunneman

Fostering Choice Awareness

A general intervention to improve patient centred decision making and fit of care

This year, Marleen received a Veni career award in medicine from The Netherlands Organisation for Scientific Research (NWO) for ‘highly promising young scientists’. The grant provides the opportunity to further elaborate free and curiosity-driven research during a period of four years.

In her project, Marleen will test the effects of a choice awareness training for oncologists on patient involvement in decision making (SDM) and fit of care (defined as how the care plan makes sense to patients and fits well in their life). The personalized training is based on the Video-Reflexive Ethnography technique. The hypothesis is that training clinicians to foster choice awareness, the first step of SDM, will lead to more patient involvement in designing care plans that fit, even without using SDM tools. This study will reveal a simple, generic, inexpensive, and effective way of individualizing care for each patient. It will be the first prospective trial in the FROST (Fostering Fit by Recognizing Opportunity Study) program.

Bjorg Thorsteindottir

Update on Minimally Disruptive Medicine

Dr. Bjorg Thorsteindottir a primary care and palliative care physician in Community Internal Medicine and a junior clinical investigator currently funded by the NIA through a k23 training grant, as well as foundation grant from Satellite Healthcare. Her project is to develop a decision aid for elderly patients with advanced chronic kidney disease to help them make treatment choices that align with their goals and values. Dr. Thorsteindottir has worked closely with our designers Ian Hargraves and Kevin Shaw and patient advisory group to come up with a prototype that is currently being tested in the Mayo Clinic Chronic Kidney Disease Clinic. The decision aid is informed by qualitative interviews with patients and focus groups with patients and clinicians on the role and perceived value of risk prediction in primary care (poster presented at ASN kidney week). It also relies on an internationally validated dialysis risk predictor from Dr. Tangri with whom we are collaborating as well as prognostic tools for incident dialysis patients that we have identified through a systematic review (currently under review) and validated in our existing cohort of elderly dialysis patients (poster presented at ASN kidney week). Dr. Thorsteindottir also works on Care Transitions for High Risk Elderly Patients and published an article titled Care Transitions Program for High-Risk Frail Older Adults is Most Beneficial for Patients with Cognitive Impairment in the Journal of Hospital Medicine. Dr. Thorsteindottir is gaining recognition as an expert on the ethics surrounding the initiation and discontinuation of dialysis and was invited to give a panel presentation at ASN kidney week titled: Dialysis in the elderly – should there be limits. Her team was recently awarded the CCATS Advance the Practice Award to move dialysis risk prediction into primary care.
3) Conduct a pilot randomized control trial (N=54) to compare the effect of D-Homes (weekly phone/in-person sessions over 12 weeks) vs. enhanced standard care (identify/reinforce care team, printed educational materials) on medication adherence, glycemic control, and health care utilization.

These aims follow a sequential exploratory mixed methods approach. The protocol will be developed using Aim 1 qualitative data and existing evidence-based models and interventions to improve medication adherence. It will be further refined using test case data and input from a multi-stakeholder participatory research team. The team consists of community members with lived experience of type 2 diabetes and unstable housing and multi-disciplinary health care and social service providers and will guide all steps of the study.

More than eight million Americans each year experience unstable housing and/or homelessness; this includes 44% of all adults seen at community health centers. The chronically homeless have a 5- to 10-fold increased risk of premature death and high health care costs (driven by acute emergency department and hospital visits). People with type 2 diabetes who experience homelessness have worse glycemic control and are hospitalized for diabetes complications a decade earlier, and with more frequency, than their housed peers. The objective of this grant is to reduce these diabetes health disparities. The aims are to:

1) Develop the initial Diabetes Homeless Medication Support (D-Homes) treatment manual through focus groups with DH (N=30) at various levels of glycemic control (HgA1c<7, 7-9, >9) and interviews with their multi-disciplinary providers (N=12),

2) Test patient perceptions of the feasibility and acceptability of study procedures and refine the D-Homes treatment manual through test cases (n=10), and

3) Conduct a pilot randomized control trial (N=54) to compare the effect of D-Homes (weekly phone/in-person sessions over 12 weeks) vs. enhanced standard care (identify/reinforce care team, printed educational materials) on medication adherence, glycemic control, and health care utilization.

The results will be applied using the multiphase optimization strategy to develop and pilot test a clinic-based, multi-component behavioral intervention – engineered to reduce patient workload, augment patient capacity, and thereby optimize patient-centered care for complex patients with T2DM and depression (Aim 3). This robust K23 research and training plan will support the development of Dr. Rogers’s expertise in patient-centered outcomes research, mixed methodology, and clinic-based intervention development and evaluation while establishing support in the advancement of patient-centered care quality for at-risk patients, and the testing of practical and sustainable strategies for improving care delivery and health outcomes in diabetes.
Thank you to our extended family!