Year Four has brought many changes to the UManage Center for Building the Science of Symptom Self-Management. We have reconfigured our leadership team. Dr. Benjamin Marlin from the College of Information and Computer Sciences has joined the team as a co-investigator. Dr. Rebecca Spencer, from the Department of Psychological and Brain Sciences and Dr. Karen Kalmakis from the College of Nursing have been appointed co-directors of the Pilot core. These changes and additions to our leadership team have provided renewed energy for the last two years of the P20 grant, and new eyes to look toward the future for the UManage Center.

In the fall, we held our first virtual mid-year External Advisory Board meeting. This was the first time our new team and our External Advisory Board had met. We were able to talk about progress to date and the plans for Year Five. The energy and enthusiasm from all who attended the meeting were high.

One of the biggest changes is that instead of new pilots for Year Five, we invited current pilot principal investigators to expand their studies. We were also awarded additional funding for an administrative supplement to expand our research in sleep self-management to a new population of individuals who experience mild cognitive impairment and their caregivers. As we enter Year Five, we are actively engaged in determining what happens next!

Cynthia Jacelon, PhD, RN-BC, CRRN, FGSA, FAAN
UManage Center Director & Principal Investigator

The UManage Center

The UManage Center for Building the Science of Symptom Self-Management is comprised of a team of interdisciplinary scientists at the University of Massachusetts Amherst seeking to develop and implement technology focused on fatigue and impaired sleep to help people manage symptoms of chronic illness.

The UManage Center is funded by a five-year, $1.23 million grant awarded to the College of Nursing at UMass Amherst by the National Institute of Nursing Research (NINR). Its overall goal is to build capacity for managing symptom self-management by developing wearable, handheld, or other advanced technologies for the early self-identification, self-reporting, and self-monitoring of symptoms to decrease the functional limitations of chronic conditions, thereby improving overall wellness and reducing health-care costs. Studies will test such devices and technologies to monitor fatigue or sleep-pattern changes and help patients decide when and how to modify their activities.

To achieve this, the UManage Center is funding a range of pilot research studies over five years for nurse-led interdisciplinary teams to develop and test technology for self-management, design population-based studies, and expand their research capacity to work with interdisciplinary research teams in order to help individuals improve their health.

Cynthia Jacelon of the College of Nursing is the principal investigator and director of the UManage Center. She is also the head of the Administrative core. Jenna Marquard of the Department of Mechanical and Industrial Engineering heads the Human Factors core. In August 2019, Rebecca Spencer and Karen Kalmakis replaced Annette Wysocki as co-directors of the Pilot core, and Benjamin Marlin, an expert on machine learning-based analytics for clinical and mobile health data, replaced Deepak Ganesan as a co-investigator on the Administrative core. These people are joined on the UManage Center Executive Administrative Committee by Ian Cooke, project manager, and Nancy Lattinville, business manager, from the College of Nursing, and Peter Reinhart, director of the Institute for Applied Life Sciences (IALS). IALS plays an important role to advance interdisciplinary research to improve human health and wellbeing on this campus.
The Three Cores in Year Four

The UManage Center achieves its aims through three core sections: the Administrative core, the Human Factors core, and the Pilot core. The Administrative core provides day-to-day management of the programs. The Pilot core helps nurse scientists develop their programs of research in wearable and handheld devices designed to support individuals with self-management of symptoms of chronic conditions. Finally, the Human Factors core provides support to the pilot projects by providing expert knowledge on the relationships among individuals, self-management strategies, wearable and handheld devices and activities, and the contexts in which these activities occur.

In Year Four, each core has built on the experiences developed over the past three years. The Administrative core was responsible for the Center’s first conference, Managing, Measuring, and Monitoring: Critical Issues in Activity, Sleep, and Fatigue, held in March 2019, and it facilitated the virtual meeting with the External Advisory Board in September 2019. It also continued to expand research capacity through various educational offerings. The Pilot core under Dr. Rebecca Spencer and Dr. Karen Kalmakis renewed its focus on grantsmanship and, in collaboration with the Administrative and Human Factors cores, conducted planning and review meetings with past and current pilot PIs to discuss progress and develop timelines and milestones for the dissemination of research. These were held alongside regular meetings to guide pilot PIs in the implementation and administration of their research.

Year Two pilot PI Dr. Mary Paterno has concluded her project and is working on the dissemination of results. The other Year Two pilot PI, Dr. Reanne LeBlanc, has completed data collection and is in the process of analyzing study data. Year Three pilot PI Dr. Jeungok Choi has completed two of her aims, and is about to finish the data collection for her third aim, a feasibility study. The other Year Three pilot has now been reassigned; Dr. Karen Giuliano is currently preparing her proposal. Lower limb mechanical compression device usability: A comparison of two devices on sleep quality. The Year Four pilots are well underway; both Dr. Heather Hamilton and Dr. Carrie-Ellen Briere are in the process of recruiting and collecting data at the same time. For the Year Five pilot, following the recommendation of our External Advisory Board and after consultation with the NINR program officer, the Pilot core invited existing pilot PIs to submit proposals to expand on their current pilot studies. The aim of this is to further strengthen the size, scope, and extent of these studies to provide strong preliminary data for an R21 or R01 grant application. After a review of applications, the Pilot core invited Dr. Choi and Dr. Briere to write full proposals aimed at extending their current pilots for submission to NINR. The Human Factors core, led by Dr. Jenna Marquard, has continued to play an active role in the pilot projects. Dr. Marquard has contributed to the pilot PI planning meetings and submission reviews to ensure that human factors issues are at the forefront of the design and implementation of each project.

Year-Four Activities

On March 28, 2019, the UManage Center held its first conference, Managing, Measuring, and Monitoring: Critical Issues in Activity, Sleep, and Fatigue in the Institute for Applied Life Sciences Conference Center on the University of Massachusetts Amherst campus. Co-sponsored by the Center for Personalized Health Monitoring, this event brought together more than 50 scientists, engineers, nurses, entrepreneurs, and students to discuss the state of the science of using technology in the self-management of activity, sleep, and fatigue. A highlight of the day was the lively facilitated lunchtime discussions that looked at innovation, sleep science, activity measurement tools, technochauvinism and its implications for health equity, and self-management/self-monitoring.

Members of the UManage Center have continued to give presentations in a variety of settings. Most notably, both Year One pilot PI Dr. Rachel Walker and Dr. Benjamin Martin spoke at the Council for the Advancement of Nursing Science 2019 conference on The Expanding Science of Sensor Technology in Research. Dr. Walker offered expertise to a panel on Theoretical Underpinnings of Sensor Technology in Research, and Dr. Marlin contributed to a discussion on Analytics in Sensor Technology in Research. The UManage Center has also maintained its collaboration with the College of Nursing’s Office of Research to hold seminars designed to expand knowledge and understanding of symptom self-management within the college and across the UMass Amherst campus.
In September 2019, the National Institute on Aging awarded the UManage Center an Administrative Supplement to extend the aims of the center to a new population. This project focuses on community-dwelling individuals with mild cognitive impairment (MCI) and their primary live-in caregiver. The intention is to test a novel intervention using personal sleep monitoring devices (PSMD) with dyads comprised of individuals with MCI and their primary live-in caregiver to improve the sleep patterns of both. The specific aims are: 1) Establish the feasibility of sleep self-monitoring using PSMDs, as a self-management strategy, to improve sleep patterns of an individual with MCI and their primary caregiver. 2) Establish the feasibility of PSMD data sharing among members of the dyad to improve sleep self-management and thus improve sleep quality among dyads; and 3) Evaluate the usability of PSMDs and data sharing for dyads comprised of individuals with MCI and their primary caregiver. Two graduate research assistants are currently in the process of recruiting subjects for the study.

Elena Smithline
Seccor parameters of persistent cancer-related fatigue: biomarker detection using computational eyeglasses.

Principal Investigator: Rachel K. Walker

Collaboration provides the perspective of looking at problems through different lenses. Dr. Walker’s research study did just that. As a research assistant in Dr. Walker’s study, I was part of a bigger group that included computer engineering, mechanical and industrial engineering, psychology and brain sciences, public health, and a fatigue specialist from Mass General Hospital. Their input not only made this a stronger study, it reinforced the need to find a common language to communicate. The experience also taught me about team dynamics, the importance of understanding each other’s field of language, and the empowerment of everyone having the same goal. I have learned about the different phases of developing a study in the nursing PhD classroom. Still, the RA position has given me the ability to use my knowledge to participate, analyze, and contribute to the research. As an RA, I presented some of our findings at the annual Gerontological Society of America conference. This meeting provided not just networking, but the ability to disseminate the information. This experience confirmed that this is where I want to be.
Graduate Research Assistant Experiences

**Favorite Iradukunda**
Sleep self-management in pregnancy using a personal health monitoring device. Principal Investigator: Mary Paterno

My primary goal when I joined the PhD program at the UMass Amherst College of Nursing was to become an outstanding researcher! It did not take me long to realize that the journey to becoming an excellent researcher goes way beyond formal doctoral education. It is a lifelong journey shaped by numerous experiences. Working with Dr. Paterno and being part of the UManage Center gave my journey a strong start. Through our pilot on sleep self-management during pregnancy, I gained tremendous experience in every aspect of the research process. This was made possible by a positive learning environment created by Dr. Paterno. I was welcomed and respected as an equal member of the team. I was trusted and valued for my contribution to the team was deeply valued. I was welcomed and respected as an equal member of the team. I was trusted and valued for my contribution to the team was deeply valued. I was welcomed and respected as an equal member of the team. I was trusted and valued for my contribution to the team was deeply valued.

**Maral Torossian**
Self-management of sleep among older adults using personal monitoring: A feasibility study. Principal Investigator: Raeann LeBlanc

As a PhD candidate, I constantly seize the opportunity to be engaged in research projects that fit my area of interest, so I can become a competent nurse researcher. I am grateful for the opportunity I had to work with Dr. LeBlanc on this pilot study, which was related to sleep self-management in older adults using a sleep self-monitoring device. I was involved in different phases of the research process, including recruitment, data collection, data entry, and writing of the manuscript for publication, all of which have added great value. I became aware of the challenges the researcher faces, especially in recruitment, and of the various strategies, sites, and resources for recruitment.

In addition, I was able to experience and acknowledge that data collection is not a smooth process. There can be multiple missing data points around which decisions should be made for analyses, in addition to technical issues that may arise (with the wrist-worn device in our case) and ways to overcome that. Finally, after Dr. Leblanc had the study findings, we presented our work at a conference, and wrote a manuscript about the study, which will be submitted for publication soon. This is the most rewarding part after hard work, when you can disseminate findings to others in your field. This has been a skills-building and a value-adding experience that any PhD candidate looks forward to.

**Jean Cody**
A tablet-based simple walking intervention to improve self-management of rheumatoid arthritis (RA) fatigue. Principal Investigator: Jeungok Choi

My experiences as a research assistant with Dr. Choi on this pilot project has made a large impact on my nursing research growth and development. I came to the UMass Amherst nursing PhD program to develop my research abilities. The coursework gave me a solid research foundation and the UManage Center pilot provided the opportunity to develop and apply my research knowledge and skill. Through my work on this project, I have been part of the team and experienced many important aspects of the research process. I was able to work with research team members from other disciplines (engineering and psychology) to develop and test the intervention prototype. I participated in developing and implementing the recruitment plan to screen and enroll eligible clients. I worked under Dr. Choi's supervision to develop research materials to enable accurate and consistent data collection. I also worked with enrolled clients through the ten-week study and participated in the data analysis. My experience will lead to my inclusion in a publication.

Working on this pilot project with experienced researchers like Dr. Choi is essential for the novice PhD researcher. I have grown professionally and am grateful for this experience.

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Pilots in Progress: Years 2 and 3

**Self-management of sleep among older adults using personal monitoring: A feasibility study. Principal Investigator: Raeann LeBlanc**

This study was IRB approved in February of 2019 and we completed data collection in August 2019. The primary aims are to 1) Evaluate the feasibility of using a Personal Sleep Monitoring Device (PSMD) to self-monitor sleep among persons age 65+, 2) Determine if sharing sleep data with chosen social network (shared self-monitoring) improves sleep self-management, and 3) Evaluate usability experience. Twenty-six persons self-identified as 12 males and 14 females and with a mean age of 72 were recruited over three months. Ninety-two percent of participants completed the study and reported improved awareness of sleep patterns and all identified a sleep goal. All participants used the PSMD as directed. There were no statistically significant changes in sleep disturbances scores or sleep quality outcomes attributed to the small sample sizes. There were small effect size changes noted in the group that shared their sleep data and among those that only used a sleep diary. User experience varied based on performance expectations that were very specific to the device (battery life, features, accuracy) that can be improved. Personal sleep monitoring among older people to support sleep self-management is feasible.

Further research can extend this study to add socially supported interventions and engineer improvements in personal sleep self-monitoring devices for older people to support sleep health when used in combination with personally tailored behavioral sleep health interventions. Two graduate students and one undergraduate honors student have been highly involved in this project. We have given these presentations and there are four manuscripts in process.
A tablet-based simple walking intervention to improve self-management of rheumatoid arthritis (RA) fatigue.

Principal Investigator: Jeungok Choi

The purpose of this study is to develop a tablet-based cognitive behavioral intervention application that improves self-management of fatigue among patients with rheumatoid arthritis. The PI has completed the first and second aims, and the third aim is in progress. First, the PI developed five weeks of cognitive behavioral therapy (CBT) educational modules for fatigue management and simple walking activity instructions with assistance from Dr. Brintell, a psychologist with expertise in CBT and Dr. Abelson, a psychiatric nurse practitioner. In collaboration with Dr. Marquard and Ms. Planteau (Engineering RA), Dr. Choi then developed the cognitive behavioral intervention mobile application and implemented this into ten mini-tablets. This was followed by two phases of usability testing by older adults with fatigue leading to revisions and refinements to phases of usability testing by older adults with fatigue. Ten mini-tablets were used and two mobile applications were developed. Data collection has gone well with the first participants and we expect data analysis to begin in the next month for the milk samples. We have expanded our community networks for recruitment and expect recruitment to increase in the coming month. In the next four months we expect to complete enrollment and begin all sample processing and analysis. We are also working on a preliminary review paper related to our aims which we will submit for publication prior to May 2020.

Monitoring and self-management of sleep, fatigue, and dyspnea to improve heart failure outcomes.

Principal Investigator: Heather Hamilton

This study will test whether daily monitoring of fatigue and sleep using a wrist-worn device can improve self-management and aid in the early detection of the signs and symptoms of circulatory fluid overload (CFO) in individuals with heart failure (HF). The study is at 80% enrollment. The first aim is to evaluate the ability of HF patients to continuously wear a wrist-worn device (Readiband) for up to 42 days to monitor fatigue, activity, sleep, and the second aim is to determine if HF patients can use and interpret the data obtained from a wrist-worn device on their level of fatigue, activity, sleep, and other symptoms to self-manage symptoms. To date participants have shown that they can interpret the data obtained from the Readiband and over time their level of sleep has improved, and their cognitive fatigue has declined. The final aim, to determine if objectively measured data on fatigue and sleep obtained using a wrist-worn device correlates with subjective measures of fatigue and sleep using PROMIS measures and other symptom data obtained using a smartphone correlates with subjective measures using PROMIS, is currently in progress.

The impact of sleep deprivation on human milk composition.

Principal Investigator: Carrie-Ellen Briere

The purpose of this study is to explore the relationship between mother’s sleep loss and human milk composition. If the relationship exists, interventions to improve self-management of sleep loss and sleep deprivation in new mothers will be tested.

We recruited our first participant in October 2019 and have now finished data collection for two dyads (two mothers, two infants) and are actively recruiting for participants. Data collection has gone well with the first participants and we expect data analysis to begin in the next month for the milk samples. We have expanded our community networks for recruitment and expect recruitment to increase in the coming month. In the next four months we expect to complete enrollment and begin all sample processing and analysis. We are also working on a preliminary review paper related to our aims which we will submit for publication prior to May 2020.

Year Three Replacement Pilot Project

Lower limb mechanical compression device usability: A comparison of two devices on sleep quality.

Principal Investigator: Karen Giuliano

Karen Giuliano, PhD, RN, MBA, FAAN, is an Associate Professor at the College of Nursing and Institute for Applied Life Sciences, and a nurse researcher whose program is focused on medical device design and innovation.

The long-term goal of this research is to develop and test an intervention model to promote self-management of sleep during various thrombosis prevention after total joint replacement. Prevention of venous thrombosis is an important part of postoperative care, and includes anticoagulant medications and/or mechanical compression of the lower limbs using external mechanical compression for a minimum of 10-14 days. Unfortunately, anticoagulants increase the risk of bleeding and compliance with current external mechanical compression devices is poor due to lack of comfort, excessive noise during operation, and mobility design especially for home use, interference with mobility and sleep disruption. Consequently, there is a need for a mechanical compression device that can be used successfully both in the hospital and at home to achieve optimal deep vein thrombosis prophylaxis, promote mobility, and minimize sleep disturbance to enhance success in self-management after total joint replacement.

The specific objective of this proposed research is to compare the impact of two mechanical compression devices on overall sleep quality. The plan for this pilot study is a comparison of the Kendall® and the Recovery Force, MACFTM. The study will first compare overall sleep quality between the two devices, using the UMass Amherst sleep monitoring lab. It will then compare the cognitive workload associated with in-home participant use between the two devices.

Year Five Pilot Projects

Following a review process, the UMass Center accepted the proposals by Dr. Jeungok Choi and Dr. Carrie-Ellen Briere and is currently working with them to complete submission to NINR.

Dr. Choi’s project will expand her research into a tablet-based simple walking activity intervention using a cognitive behavioral therapy approach (CBT), shifting from a focus on the individual to a group approach. This project will revitalize the tablet-based cognitive behavioral intervention (Tab-CBI) previously focused on the individual by adding a group CBT component for this study, referred to as Tab-CBI Group. The first aim will examine the effect of Tab-CBI Group, compared to those receiving usual care on (a) daily sleep and fatigue level (primary outcomes), and (b) self-efficacy and quality of life (secondary outcomes). The second aim will examine the effect of Tab-CBI Group, compared to those receiving Tab-CBI Individual, on primary and secondary outcomes.

The study findings will contribute to development of a mobile-based fatigue management strategy that produces a long-term effect, thereby advancing the field of arthritis fatigue management. It is anticipated that the results will provide a strong foundation for developing a mobile-based fatigue management suitable to other contexts, such as cancer-related or postoperative fatigue.

Dr. Briere’s project will further her research into the composition of human milk under conditions of maternal sleep deprivation, and the effect of this on infant development and maternal stress. The extended project will increase the sample size and take the next steps to design self-management strategies for mothers in the postpartum period. To do this, it will be critical to understand the maternal experience with sleep and any present self-management strategies, as well as understand the perspectives of professionals who work with mothers and may provide sleep advice. After milk analysis from Years 4 and 5, this qualitative data from mothers will provide essential knowledge for Dr. Briere’s team to identify areas for intervention to help mothers increase their self-management of sleep hygiene postpartum. Additionally, interviews of breastfeeding experts and sleep experts will provide essential knowledge for what is communicated to mothers. Once more is known about the maternal experience and there is a better understanding of the professional views on sleep postpartum, Dr. Briere will be able to develop pilot interventions that will improve maternal sleep in the postpartum period.

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