Year Three at the UManage Center for Building the Science of Symptom Self-Management was highly successful. We continued our pilot program and planned our first conference, “Managing, Measuring, and Monitoring: Critical Issues in Activity, Sleep, and Fatigue.” Our Administrative Core focused on evaluating the activities of Year Two and enlarging our presence in the College of Nursing, across the campus, and within the NINR Center Directors group.

At the beginning of Year Three, I was privileged to convene the Annual NINR P20 and P30 Directors’ Meeting, which focused on technology for self-management. The UManage Center was also prominent in the Center Director’s manuscript derived from the meeting. Our Pilot Core is very active. Among our UManage Fellows, some have completed their pilots, pilot investigators from Year Two and Year Three are engaged in their research, and Year Four pilot principal investigators are finishing their proposal development. Several of our pilot investigators have submitted grants based in part on their UManage Center experience. Our Human Factors Core continues to be an inspiration for study design. Dr. Jenna Marquard has been instrumental in guiding the design of its pilot projects. As we look forward to Year Four, we are a fully developed center focused on sustainability.

Cynthia Jacelon, PhD, RN-BC, CRRN, FGSA, F A A N
UManage Center Director

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 who are seeking to develop and implement technology to help people manage symptoms of chronic illness, especially fatigue and impaired sleep.

The UManage Center is funded by a five-year, $1.23 million grant awarded to UMass Amherst’s College of Nursing by the National Institute of Nursing Research (NINR). Its overall goals are to improve overall wellness, reduce health-care costs, and decrease the functional limitations of chronic conditions by developing wearable, handheld, or other advanced technologies for the early self-identification, self-reporting, and self-monitoring of symptoms.

To achieve this, the UManage Center over the course of five years is funding a range of pilot research studies for nurse-led interdisciplinary teams to develop and test technology for self-management, design population-based studies, and collaborate with interdisciplinary research teams. Studies will test devices and technologies that enable patients to monitor their fatigue or sleep-pattern changes and decide when and how to modify their activities.

Cynthia Jacelon of the College of Nursing is the principal investigator and director of the UManage Center and the head of the Administrative Core. Her College of Nursing colleague Annette Wysocki is the director of the Pilot Project Core. Jenna Marquard of the Department of Mechanical and Industrial Engineering heads the Human Factors Core. They are joined on the Executive Committee by sleep expert Rebecca Spencer from the Department of Psychological and Brain Sciences, big-data specialist Deepak Ganesan of the College of Information and Computer Sciences, project manager Ian Cooke from the College of Nursing, and Peter Reinhardt, director of the Institute for Applied Life Sciences (IALS), which plays an important role in advancing interdisciplinary research to improve human health and well-being at UMass Amherst.
The Three Cores in Year Three

The UManage Center has three core sections: the Administrative Core, the Human Factors Core, and the Pilot Project Core. The Administrative Core provides day-to-day management of the programs. The Pilot Project Core helps new nurse scientists develop research programs in wearable and handheld devices to help individuals with chronic conditions self-manage their symptoms. Finally, the Human Factors Core supports the pilot projects by providing expert guidance on relationships among individuals, self-management strategies, wearable and handheld devices, and research activities.

Throughout Year Three, each of the three cores continued to help build capacity in symptom self-management science. The Administrative Core, guided by the principal investigator and the Executive Committee, continued to engage with industry and facilities serving older adults and to expand research capacity through educational offerings. It also focused on planning the conference “Managing, Measuring, and Monitoring: Critical Issues in Activity, Sleep, and Fatigue,” to be held March 28, 2019.

The Pilot Project Core, under Dr. Annette Wysocki and in collaboration with the Administrative and Human Factors Cores, continued to foster the development of pilot project teams. Dr. Wysocki held regular meetings with pilot PIs to coach them in the implementation and administration of their research and to discuss the design of presentations, possible venues for publications, and future research proposals.

The Year One pilot projects, led by Dr. Rachel Walker and Dr. Karen Kalmakis, have concluded their studies and are disseminating their results. Year Two pilot PI Dr. Mary Paterno and her research team are analyzing their study data. In December, Dr. Roseann Leffranche received NINR approval for “Self-Management of Sleep Among Older Adults Using Personal Monitoring: A Feasibility Study”; she is now beginning her research. Dr. Jeungrak Choi has been testing devices for her Year Three pilot project, “A Tablet-Based Simple Walking Intervention to Improve Self-Management.” A second Year Three project, led by Dr. Beth Heineman, has been postponed until Year Five. Looking ahead, the Pilot Project Core has selected the Year Four pilots, guided the creation of their proposals, and mentored the new investigators in writing and submitting their grant applications.

The Human Factors Core, led by Dr. Jenna Marquard, has infused its approach into all aspects of the UManage Center and worked with the pilot principal investigators to elucidate their projects’ human factors issues. Dr. Marquard has contributed to grant reviews and consultations for the Year Three and Four pilots, ensuring a human-factors, participatory approach to each project’s technology design and implementation. She also gave the keynote address at the NINR Center Directors Meeting in May of last year.

Managing, Measuring, and Monitoring: Critical Issues in Activity, Sleep, and Fatigue

The UManage Center worked throughout the year planning its first conference, which will take place Thursday, March 28, 2019, in the Life Sciences Laboratories Conference Center at the University of Massachusetts Amherst.

This daylong conference has been created for innovators in industry, academia, and health care seeking to make a real-world impact by combining the best evidence, technology, and symptom science in a human-centered manner. It will be an opportunity for nurses, engineers, scientists, and entrepreneurs to discuss the state of the science in the self-management of activity, sleep, and fatigue using technology and to explore the use of technology, devices, and standards for measurement to advance our understanding of critical issues in these areas.

The day will feature keynotes from Dr. Lisa Wood, RN, of the MGH Institute of Health Professions and Dr. Matthew Buman of the College of Health Solutions at Arizona State University. There will also be speakers from industry, the UManage Center, and the Institute for Applied Life Sciences (IALS), a poster session, and opportunities for interactions with the experts.

The conference is organized by the UManage Center and is cosponsored by the Center for Personalized Health Monitoring, housed in the Institute for Applied Life Sciences at the University of Massachusetts Amherst.
**Year Three Activities**

An early Year Three highlight was the contribution of the UManage Center members to the 2018 NINR Center Directors Meeting that took place at the National Institutes of Health campus in Bethesda, Maryland. Held May 1, 2018, it focused on how NINR Centers are advancing symptom and self-management science using personalized precision health and technology.

Dr. Jacelon chaired the meeting. Dr. Marquard, director of the Human Factors Core, was the keynote speaker and delivered a talk, “Opportunities for Personalized Precision Health Technology Use in Health Monitoring.” Year One Pilot Project PI Dr. Karen Kalmakis contributed one of the meeting’s two presentations on pilot projects. The UManage Center as a whole presented “Building Research Capacity,” a poster exploring the theme of the pilot project process. Dr. Mary Paterno presented a poster on her Year Two pilot project. Dr. Jacelon and Dr. Angela Starkeyreather of the University of Connecticut led the development of the Center director’s manuscript, “The Use of Technology to Support Precision Health,” now under review.

**EDUCATIONAL OPPORTUNITIES**

Over the past year, the UManage Center continued to run seminars in collaboration with the College of Nursing’s Office of Research to expand knowledge and understanding of symptom self-management within the college and across the UMass Amherst campus (see table below). Dr. Kalmakis presented on her pilot research in September. Dr. Paterno is scheduled to present in April. The UManage Center has also welcomed faculty from across the UMass Amherst campus whose research relates to its goals. Dr. Trisha Andrew of the Department of Chemistry spoke about her work on how off-the-shelf garments, textiles, and threads can be nondestructively transformed into electronic circuit components using reactive vapor deposition. Dr. Christopher Martell, who is working with Dr. Choi on her Year Three pilot, discussed the work of the UMass Psychological Services Center and how it engages with researchers on campus. Finally, Dr. Jun Yao of the Department of Electrical and Computer Engineering spoke about his lab’s work on synthesizing and engineering nanoscale materials to enable novel devices and sensors and their integration on rigid or soft frameworks for functional electronic or bioelectronic systems.

**GRANT APPLICATIONS AND MANUSCRIPTS**

Throughout Year Three, members of the UManage Center have generated grant applications and been involved in preparing manuscripts. Dr. Jasen and Year Two Pilot PI Dr. LeBlanc continued the UManage Center’s collaboration with Philips Research North America. Their National Institutes of Health R21 grant submission, “Activating the Circle of Care: Exploring a Model of Technology-Enabled Palliative-Care Symptom Management for Cynapex,” was scored and the team resubmitted it in October.

Dr. Jasen also submitted a second R21 application with Year Three Pilot PI Dr. Choi and College of Nursing faculty member Dr. Yeonik Noh. UManage Fellow Dr. Paterno has submitted one R21 application as principal investigator, co-investigator on a second R21 submission and was also involved in an R33 application. Dr. Kalmakis has submitted an R01 grant application, “A Multimodal Assessment of Stress Response Mechanisms Underlying Learned Resilience Program,” drawing on research from her pilot project study. Finally, Dr. Walker is co-PI on an NSF submission with Dr. Sarah Perry of UMass Amherst’s Department of Chemical Engineering.

In addition to having co-authored the Center Director’s annual manuscript, Dr. Jasen was the second author of the publication “Chronic Illnesses and Fatigue in Older Individuals: A Literature Review,” by CON doctoral student Maral Towarian. A second CON doctoral student, Celalina Vitali, is working on a manuscript on mentoring.

**OTHER SUCCESSES**

UManage Fellows have also enjoyed career-advance successes over the past year. In June 2018, Dr. Walker became the first co-author selected by the American Association for the Advancement of Science (AAAS) and the Lemelson Foundation as an AAAS/Lemelson Invention Ambassador. She was also recently awarded an Oncology Nursing Foundation grant for her proposal, “Describing Eye-Movement Changes Associated with Cancer-Related Fatigue Using a Wearable Technology,” written in collaboration with Dr. Sarah Perry. Finally, Dr. Walker was a co-awardee on UMass Lowell’s MBZ0695X Medical Device Innovation Challenge for a proposal developed with Michael Bueh, the IALS Human Testing Center director.

Dr. Paterno recently received a Health Resources and Services Administration Prize in response to a Maternal and Child Health Bureau Grand Challenge, “Addressing Opioid Use Disorder in Pregnant Women and New Moms,” for her proposal, “The Use of Wearable Technology in Increasing Hope and Supporting Sustained Recovery for Pregnant and Parenting Women with Opioid-Use Disorder.” In addition, several PhD students have been actively involved with the UManage Center pilot research projects.
The Pilot Project Process

The UManage Center’s Pilot Project process consists of three key phases:

1) Pre-award development
2) Award supervision
3) Post-award management

The pre-award process begins in May, when a request for applications is sent to College of Nursing faculty. This provides full details of the opportunity and clear guidelines and a time frame for submission. An informational session is then held, after which prospective principal investigators submit letters of intent. After these are reviewed, Dr. Wysocki sends out notifications to submit full grant applications. The UManage team then begins the mentoring process. Dr. Wysocki and Dr. Jacobson work with the selected PIs to develop their proposals. Dr. Marquard provides Human Factors consultation, and Dr. Rebecca Spencer provides guidance on sleep monitoring. Applicants also meet with support staff from the College of Nursing Office of Research and Business Offices to prepare their budgets and budget justifications. Once the full applications have been developed, the core directors conduct a mock review of each proposal and offer comments for improvement. When the applications have been revised, the UManage Center team works with the PIs on their final submissions to the National Institute of Nursing Research.

The second part of the process entails award supervision. Dr. Wysocki meets regularly with the current pilot PIs to discuss the implementation and management of their research studies. She provides ongoing consultation to address recruitment challenges, the engagement of community partners, and day-to-day data management and collection strategies. The Office of Research also provides PIs with support in the management of their budgets. Once pilot PIs have completed their studies, they become UManage Fellows. Dr. Wysocki holds check-in meetings to talk about their future plans and generating funding to advance their projects. The Office of Research as a whole supports fellows in their subsequent endeavors and continues to track their achievements.

Year One Pilot Projects

The Year One Pilot PIs have completed their projects and are in the process of disseminating their findings.

Real-Time, Continuous Cortisol Monitoring: Possibilities for Stress Self-Management
Principal Investigator: Rachel K. Walker

Focused on the use of wearable eye-tracking technology to detect errors in saccadic parameters potentially associated with subjective reports of fatigue in breast cancer survivors. Additional funding for this study was obtained from the Pires of Hope Center for Breast Cancer Research. Dr. Walker presented preliminary results at a symposium at the annual meeting of the Gerontological Society of America, held in Boston in November 2018.

Year Two Pilot Projects

Sleep Self-Management in Pregnancy Using a Personal Health-Monitoring Device
Principal Investigator: Mary Paterno

A clinical trial exploring the use of a personalized health-monitoring device to improve sleep during pregnancy. The research team used the Misfit Shine 2 to track daily sleep and physical activity among pregnant women (n = 24) from 24 to 36 weeks gestation. All study participants were taught behavioral modifications to improve sleep in pregnancy, delivered by a registered nurse. Participants were then randomized to the intervention or control group. Women in the intervention group were given a Misfit Shine 2. Over the course of their work, the team adjusted study protocol to increase enrollment. They expanded eligibility criteria to include multiparous women and women pregnant with twins. They initially recruited participants using posters flyers, Craigslist, and two UMass Amherst online newsletters, but these techniques were found to be inadequate. They expanded their efforts to include recruitment by distributing flyers at a local OB/GYN office and through Facebook, targeting women of childbearing age within a 60-mile radius of Amherst. All data collection was completed in August 2018 and the research team is now analyzing study data.

Self-Management of Sleep among Older Adults Using Personal Monitoring: A Feasibility Study
Principal Investigator: Raeann LeBlanc

The central premise of this research is that sleep quality and health outcomes (physical functioning, anxiety, depression, fatigue, sleep disturbance, social role, pain interference, and pain intensity) can be improved in older adults by using a personal sleep monitoring device (PSMD), a technology-based intervention, and a social network intervention, where data is shared among users. This research is the first step in designing a novel social-network approach to personal health monitoring among older adults. Expected outcomes for this feasibility study are the successful recruitment and retention of older adults to participate, use a PSMD, share data with social network members, influence positive self-management, and show health benefits. Long-term expected outcomes are that older adults using PSMDs will have improved sleep quality and utilize social-network data sharing to improve self-management. These outcomes will improve overall health and physical function, leading to better overall health self-management. By demonstrating the effective use of PSMDs, the aim is to lay the groundwork to design and refine larger subsequent studies examining the use of PSMDs to improve self-management of sleep and health outcome measures through social network interventions.

Saccade Parameters of Persistent Cancer-Related Fatigue: Biomarker Detection Using Computational Eyeglasses
Principal Investigator: Karen Kalmakis

Began the process of validating a wearable, real-time, continuous, cortisol sweat sensor and used it to test the relationship between changes in cortisol and symptoms of fatigue. Additional funding for this study was obtained from the Pires of Hope Center for Breast Cancer Research. Dr. Kalmakis presented some of her findings at the 2018 NINR Center Directors meeting and gave a talk on the Biomolecular Research Informatics Computing System at the 2018 Eastern Nursing Research Society conference.

Evaluation of a Mobile App for Promoting Physical Activity in Pregnancy
Principal Investigator: Karen Kalmakis

Pregnancy-induced fatigue and a lack of physical activity are common during pregnancy. A clinical trial exploring the use of a personalized health-monitoring device to improve sleep in pregnancy. The research team used the Misfit Shine 2 to track daily sleep and physical activity among pregnant women (n = 24) from 24 to 36 weeks gestation. All study participants were taught behavioral modifications to improve sleep in pregnancy, delivered by a registered nurse. Participants were then randomized to the intervention or control group. Women in the intervention group were given a Misfit Shine 2. Over the course of their work, the team adjusted study protocol to increase enrollment. They expanded eligibility criteria to include multiparous women and women pregnant with twins. They initially recruited participants using posters flyers, Craigslist, and two UMass Amherst online newsletters, but these techniques were found to be inadequate. They expanded their efforts to include recruitment by distributing flyers at a local OB/GYN office and through Facebook, targeting women of childbearing age within a 60-mile radius of Amherst. All data collection was completed in August 2018 and the research team is now analyzing study data.

The Year One Pilot PIs have completed their projects and are in the process of disseminating their findings.

Rachel K. Walker
Karen Kalmakis

Self-Management of Sleep among Older Adults Using Personal Monitoring: A Feasibility Study
Principal Investigator: Raeann LeBlanc

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The Year Two Pilot Projects
Year Three Pilot Projects

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 the self-management of fatigue among patients with rheumatoid arthritis. The research team has completed the first aim of the study, developing the Tablet-based Cognitive Behavioral Intervention (Tab-CBI) application. Here, the PI developed six weeks of cognitive behavioral therapy–based educational modules for fatigue management and simple walking activity instructions with assistance from Dr. Martell, director of UMass Amherst’s Psychological Services Center, and Dr. Abelson, a College of Nursing psychiatric nurse practitioner. The PI and her colleagues developed scripts for each learning activity and made six video recordings. Each weekly learning module consists of learning activity, video recording, self-assessment quizzes, setting up a SMART goal, homework, and appointment reminders. Dr. Choi then developed the Tab-CBI mobile application in collaboration with Dr. Marquard and Ms. Phaneuf, an engineering research assistant, using MS To-Do software. The Tab-CBI application consists of 1) weekly learning modules (including key points to remember) with video recordings, a link to Qualtrics for completing surveys, a text box for the smart goal, and reminders to synchronize and charge the tablet. The tablet with the Tab-CBI application was validated with three nurse experts in rheumatoid arthritis care management. Comments were obtained and used to refine the application.

Dr. Choi and her team are currently working on their second aim, a Tab-test. They have begun usability phase I and have collected data from four plans to do so from one more. The nursing research assistant, Ms. Coyle, person interviews with each of the four participants who have rheumatoid have tested positive for moderate to severe fatigue on the PROMIS Fatigue v1.0 Fatigue-8a and without cognitive impairment measured by Mini-Cog. comments were recorded and are being transcribed.

Self-Monitoring of Fluid Status to Improve Sleep and Reduce Fatigue in Patients with Lung Congestion Secondary to Circulatory Overload. Principal Investigator: Elizabeth Henneman

The long-term goal of this proposed study is to develop a home-monitoring system for patients at risk of developing fluid overload and lung congestion. Sleep disturbances and fatigue are common in patients with circulatory overload and lung congestion. These symptoms not only impact the patient’s quality of life but are predictors of poor outcomes. It is therefore important to develop methods of identifying early circulatory overload in at-risk patients, such as those with heart failure, renal failure, and hyperpneaemia. The ability to identify the occurrence of early hemodynamic changes and lung congestion would allow the patient and clinician to intervene early, possibly avoiding hospitalization.

What is needed is a noninvasive, hands-free system for the personalized monitoring of hemodynamic status and lung congestion that is easy to use by patients and family members in the home setting. The broader goal is to design, manufacture, and test a feasible early warning system. Part of this is the development of wearable fabrics that allow for the measurement of variables related to fluid overload. The aim of this pilot is to define the end-user requirements for these wearable fabrics. The study will determine if a wearable device will be adopted and used by patients and providers. By putting human factors at the fore-front, the intention is to design a system that patients and providers will use. This pilot project is currently on hold.

Year Four Pilot Projects

The Impact of Sleep Deprivation on Human Milk Composition. Principal Investigator: Carrie-Ellen Briere

Carrie-Ellen Briere, PhD, RN, CLC, is a human milk scientist focused on stem cells and other biometrics. The purpose of this study is to explore the relationship between mothers’ sleep loss and human milk composition. If a relationship exists, interventions to improve the self-management of sleep loss and sleep deprivation in new mothers will be tested.

Little is known about the impact of sleep deprivation on human milk composition. Such knowledge is needed to support the importance of developing interventions of self-management of sleep hygiene in the postpartum period whose nonaction might have negative health repercussions for mothers and infants. Therefore, the overarching hypothesis of this research is that better self-management of maternal sleep will improve human milk composition, and reduce signs of maternal stress. The secondary aims for this pilot study are to describe sleep patterns of breastfeeding mothers in the first four to six weeks postpartum and to analyze human milk composition longitudinally within and between mothers and evaluate potential associations with sleep loss.

Monitoring and Self-management of Sleep, Fatigue, and Dyspnea to Improve Heart Failure Outcomes. Principal Investigator: Heather Hamilton

Heather Hamilton, RN, PhD, is a nurse scientist who is committed to reducing health disparities in African American adults using technology. The purpose of this study is to 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 long-term goal of the research is to develop and improve self-management strategies leading to early detection of CFO in African American adults.

Early detection of CFO in individuals with HF remains a challenge. Sleep disruptions and fatigue are known to be associated with CFO. Therefore, early detection of fatigue and sleep disruptions may provide a window for self-management and the possibility of early intervention among adults with HF. Personalized health monitoring devices are a potential new way to track fatigue and sleep disruptions in adults with HF. The central hypothesis of this study is that the use of wearable devices will provide a self-management tool for the early detection of changes in symptoms of HF.

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