IMPACT:
RESEARCHERS TRANSFORMING PATIENT CARE

UNIVERSITY OF UTAH COLLEGE OF NURSING
Where some see challenges, we see a tremendous opportunity to continue to have a significant impact on the health and quality of life of those across the U.S. and the world beyond. Nursing science provides the evidence base to support the practice of the largest healthcare profession, as well as to improve wellness and quality of life for all individuals, regardless of age, resources, or health status.

Patricia Grady, PhD, RN, FAAN
Director of the National Institutes of Health’s National Institute of Nursing Research
A year ago, the National Institute of Nursing Research released a strategic plan identifying four areas of focus for nursing science:

- Building the Scientific Foundation for Clinical Practice
- Preventing Disease and Disability
- Managing and Eliminating Symptoms Caused by Illness
- Enhancing End-of-Life and Palliative Care

At the University of Utah College of Nursing, we know we are ahead of the curve. Core groups of our researchers are studying ways to boost caregiver resilience; alleviate patients’ chemotherapy symptoms; manage diabetes and weight; diminish health disparities; and build technology to enhance healthcare communication.

After years of working in clinical settings, nurse researchers know the questions and challenges that require scientific answers. We are driven to innovate, transform, and streamline healthcare. Nursing research is explored by creative scientists who have been present at the bedside, in patient homes, in the community and at the front of classrooms. We all are seeking ways to help our patients feel better; make healthcare teams and systems work more efficiently; and fully integrate families into patient care.

The University of Utah College of Nursing already is working in line with NINR’s strategic nursing science goals. Join us in the discovery!

A growing, but largely unseen, group of family members is quietly providing the healthcare many Americans receive.

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Most caregivers are older women. Most have other jobs. And just like professional caregivers, they’re burning out. Their patients are living longer and with chronic diseases including dementia, diabetes, heart failure and cancer that take a painful toll not just on the patients, but on those who take care of them as well.

“They are today’s silent patients,” says Linda Edelman, PhD, RN, an associate professor at the University of Utah College of Nursing whose research focuses on injuries to older adults living in rural areas. Most are women, many are part of the “sandwich generation,” providing care for aging parents while supporting their own children. Others are aging themselves. “It’s not surprising then, just like professional caregivers, family caregivers are burning out.”

Still, caregivers perform the job tirelessly and with little fanfare or complaint—often to the detriment of their own health. When the caregiving ends, many of these lay healthcare providers discover their own health problems—diabetes, heart failure, complicated grief and persistent depression.

For nearly 20 years, College of Nursing researchers have been delving into these caregivers’ experiences—how they become isolated, how they communicate with healthcare workers, and how they recover from the death of their care recipients. Using a grant from the John A. Hartford Foundation and the Gerontological Society of America, Jackie Eaton, PhD, has developed an art-based intervention using ethnography to educate caregivers and others about the burdens—and occasional joys—of caring for a family member.

“Communicating the realities of family caregiving is difficult, especially to CAREGIVERS: THE SILENT PATIENTS

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“Communicating the realities of family caregiving is difficult, especially to
family and friends who are now providing the majority of direct care,” says Dr. Eaton, an assistant professor. “Experiences that stimulate multiple senses, such as viewing a research-based play, enhance communication and create opportunities for mutual understanding.”

Together, Mike Caserta, PhD; Lee Ellington, PhD; and Kathleen Mooney, PhD, RN, explored the granting experience of families facing cancer. Through a large National Institutes of Health-funded grant completed in 2016, they examined caregiver communication with healthcare providers and tested strategies to assist family caregivers in caring for their family member and maintain their own well-being. Adapting the automated Symptom Care at Home (SCH) system, Dr. Mooney asked family caregivers to report not only the patient’s symptoms, but their own symptoms as well—sleep, fatigue, anxiety and sadness. Caregivers received automated coaching and their symptoms were monitored. Those who were coached were better able to make their family member comfortable and improve their own well-being.

“Nobody really asks the family members, ‘How are you doing?’ Mostly, healthcare professionals approach the patient, says Dr. Mooney, a distinguished professor. “Experiences that stimulate multiple senses, such as viewing a research-based play, enhance communication and create opportunities for mutual understanding.”

The core of these researchers’ work is the foundation of the college’s robust program of family caregiver science. Together, researchers are addressing family caregiver preparedness, health, psychological well-being, and adjustment to death of their family member. Researchers at the College of Nursing are passionate about developing new models of care that support the family caregiver in providing care to the patient while maintaining their health, says Dr. Ellington.

“We are leaders in caregiver research and education, ultimately to improve the care provided to families at our institution and throughout the state, and inform national models of patient-centered, family-oriented care.”

-Lee Ellington, PhD

**STUDENT PROFILE**

**WILLIAM HULL**

**Age:** 28

**Hometown:** Herriman, Utah

**Education:** BS in Nursing, 2nd-year PhD student, University of Utah

**Family:** Married to Jodi, a graphic designer and fine arts graduate from the University of Utah; father of 9-year-old Jocelyn, and 4-year-old Jesse.

**Mentors:** Drs. Kristin Cloyes, Gail Towsley, Lee Ellington, Mike Caserta.

**LGBTQ caregivers.**

Kristin Cloyes, PhD, RN, assistant dean for the PhD Program, seeks to better understand the communication and support needs of Lesbian, Gay, Bisexual, Transgender, Queer (LGBTQ) caregivers of advanced cancer patients. In particular, Dr. Cloyes hopes to gain insights about the interaction of the stresses of being a minority, resilience, community-based responses and peer-to-peer support for LGBTQ caregivers.

With a grant from the Alzheimer’s Association and Cambia Health Foundation, Kathleen Supiano, PhD, is studying the impact of group therapy on caregivers at risk for, or suffering from, complicated grief after the death of their care recipient.

“The group dynamic is critical,” Dr. Supiano says. “It requires pulling together people with very disparate lives, but one common experience—caring—and changing behavior in a positive way, changing attitudes and understanding, and developing new skills to manage living with the loss that brought you to the group. It's the difference between support and therapy.”

**WHO ARE AMERICA’S CAREGIVERS?**

- **WHAT DO THEY DO?**
- 60% female
- 24 hrs of care a week, on average
- 49 years old on average
- 23% spend 41 or more hours a week providing care
- 7% of care is 75 years old or older
- 57% perform medical/nursing tasks, including injections, feeding tubes, catheter and colostomy care

**UNIVERSITY OF UTAH COLLEGE OF NURSING**
hit television shows like “Chicago Med” and “Grey’s Anatomy” portray U.S. healthcare as a series of dramatic emergencies—a mad dash from treating the victims of catastrophic plane crashes, to domestic terrorism and then on to exotic diseases.

But the reality is much more routine, a matter of helping patients maintain their health and wellness while managing chronic diseases and conditions including diabetes, heart disease and cancer. Chronic diseases are responsible for seven out of 10 deaths each year. And one out of five Americans has a disability.

Acknowledging the state of Americans’ health, the National Institute of Nursing Research has identified preventing disease and disability and managing and eliminating symptoms of illness as two key areas of focus for nursing science.

College of Nursing researchers have taken up the charge, studying the impact of autism spectrum disorders on aging adults; reviewing nutrition and physical activity in students with disability; and developing social media and smart phone-based coaching tools to help patients with diabetes, childbirth-related pelvic floor change, and cancer manage their conditions. To track our progress, researchers have also developed a new measure of quality of life suited to the needs of people with intellectual disability.

“In some ways, the digital world has transformed how providers and patients manage chronic conditions,” says Michelle Litchman, PhD, RN. Using a grant from the University of Utah Diabetes and Metabolism Center, Dr. Litchman has developed an online peer health intervention that highlights the increased use of social media for health purposes.

“One health communities are meaningful in supporting not just the physical well-being of individuals, but their emotional well-being as well,” she says. “It’s crowdsourcing the wisdom of a collective group, and leaning on each other, to support the day-to-day management of chronic conditions.”

With a grant from the Patient-Centered Outcomes Research Institute (PCORI), Nancy Allen, PhD, RN, also is testing the efficacy of technology to address health disparities in Hispanic populations trying to manage type 2 diabetes. In the first phases of the project, Dr. Allen and her team developed an advisory board to help identify the concerns people in the community were facing related to their chronic disease. The research team also hired a community health worker as a co-investigator. Then, they added the devices – continuous glucose monitors, Fitbits, iPads, mobile phones and telehealth portals – to gauge how the technology compared to in-person interventions for their busy Latino patients.

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—Michelle Litchman, PhD, RN

“...the traditional health care model is not meeting their needs. Most can’t take time off from their jobs to go to the clinic,” says Dr. Allen. “We want to know: Is there a way to deliver care that patients can access when they have time and when it’s accessible? Can we structure this differently?”

Lauri Linder, PhD, RN, is using devices to help young patients with cancer track their pain and chemotherapy symptoms. Through an NINR grant, Dr. Linder and her team—including providers and the children themselves — are developing and evaluating a symptom assessment app. Her team is supported by the University of Utah’s
nationally recognized Therapeutic Games and Applications Lab (the GApp Lab).

“Children often have difficulty explaining their symptoms in a way that healthcare providers can understand,” Dr. Linder says. “Mobile technology offers innovative options to engage children and support them in communicating their symptoms to healthcare providers.

Over her 20-year research career, Lauren Clark, PhD, RN, has expanded her study of the cultural aspects of health disparities with team grant funding from the National Institutes of Health. “Both Mexican American and Euro-American childbearing women draw on cultural knowledge from their mothers, sisters, and friends, and that shapes how they experience physical recovery after childbirth,” Dr. Clark says. “Our team is studying pelvic floor support changes in first-time mothers, asking how cultural practices that accelerate recovery can be best supported.

30 MILLION
AMERICANS MANAGING DIABETES

1 IN 4
AMERICANS OVER THE AGE OF 65 HAVE DIAGNOSED OR UNDIAGNOSED DIABETES

1.5 MILLION
AMERICANS ARE DIAGNOSED WITH DIABETES EVERY YEAR

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12.6%
OF U.S. POPULATION IS DISABLED

35%
OF THOSE 65 AND OLDER

13%
OF THE TOTAL U.S. SCHOOL POPULATION REQUIRES SPECIAL EDUCATION SERVICES

40%
OF DISABLED ADULTS IN THE U.S. ARE OBESIDE

When you work in healthcare, patterns start to emerge: the complexity of explaining genetic testing to new parents, messages lost in the translation between emergency department staff and poison control pharmacists, the mysteries of tracking what caused a child’s asthma attack.

While healthcare workers muddle through with patches and workarounds, nurse informaticists and technology designers are developing ways to bridge those divides.

Many healthcare researchers started out as nurses, gerontologists, therapists and counselors. But they all have one thing in common—time spent with patients. At the University of Utah College of Nursing, teams of interdisciplinary researchers are combining their collective knowledge of patients’ experiences to identify the aging technology, missed cues and rote practices that impede seamless care.

Sometimes, it’s personal experience that connects a scientist to the burning question they need to answer.

The grandson of Katherine Sward, PhD, RN, started showing signs of pediatric asthma as a toddler. A nurse by training and informaticist by choice, Dr. Sward put her personal and professional experience to work spearheading the University of Utah’s $5.5 million PRISMS Center. Over the past two years, her interdisciplinary team of engineers, pediatricians, nurses and chemists have designed a digital interface for personal environmental sensors that will help families track everything a child with asthma encounters in a day—from the school custodian’s cleaning spray to the dust under the bed. The project pairs faculty researchers with Utah families to design and test equipment, software and web dashboards.

Big data and innovative technology define the research of Jia-Wen Guo, PhD, RN; Andrea Wallace, PhD, RN; Mollie Cummins, PhD, RN; and Katherine Sward, PhD, RN (left to right).

STUDENT PROFILE

DJIN LYN TAY

Age: 37

Hometown: Singapore

Education: BS in Behavioral Science; BS in Nursing; PhD candidate, University of Utah.

Family: Mother of 10-year-old Brannon, 8-year-old Keenan and 6-year-old Aiden.

Mentor: Dr. Lee Ellington

Why a PhD? When I started working as a new nurse in home care, doing initial assessments for homebound patients, I realized the urgent need for better support for seriously ill patients and families who have not yet come to terms with making plans for the end of life. I want to teach and create knowledge to help patients and families navigate through these stressful times of serious illness.

Big data and innovative technology define the research of Jia-Wen Guo, PhD, RN; Andrea Wallace, PhD, RN; Mollie Cummins, PhD, RN; and Katherine Sward, PhD, RN (left to right).
“It’s very hands-on. The parents and kids, sensor developers, and researchers are working as a team, because that’s the only way we’ll end up with something that really works,” Dr. Sward says.

Associate Dean for Research and the PhD Program Mollie Cummins’ years of experience working in emergency departments revealed the gaps in communication between hospital staff and the poison control center. Because most hospital systems and poison control centers use different software for record-keeping, continuity in poisoning patients’ care hinges on the right messages getting passed on, and post-it notes ending up in the right files.

Mollie Cummins, PhD, RN, and her team have designed a software “bridge” that would allow the pharmacists at poison control and emergency room doctors and nurses around the country to send information to each other using a secure, electronic platform.

“It’s very hands-on. The parents and kids, sensor developers, and researchers are working as a team, because that’s the only way we’ll end up with something that really works.”

Katherine Sward, PhD, RN

Dr. Cummins, a biomedical informaticist and associate professor. “In turn, we have busy doctors and nurses trying to communicate lab results over the telephone, which is similar to asking your bank to read you your bank statement.”

“Andrea Wallace, PhD, RN, has designed two studies using electronic health records. One identifies patients’ social needs while they’re in the emergency department. Then, with the help of United Way information specialists, researchers will integrate community-based and health records data to analyze how social needs may contribute to health outcomes. Dr. Wallace’s second study will link a nurse call center to diabetes patients, providing low-literate diabetes self-management and collaborative goal-setting while testing the positive reinforcement of primary care physicians.

“By harnessing the power of electronic health records technology, we hope to close gaps in communication between patients, community-based service providers and healthcare providers—and better support patients in the places where they live.”

Andrea Wallace, PhD, RN

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17% OF PATIENTS USED A SMART PHONE HEALTH APP

4 OF 5 ACUTE CARE HOSPITALS ADOPTED ELECTRONIC HEALTH RECORDS (EHRS) WITH CLINICIAN NOTES

18% OF PATIENTS USE TEXT MESSAGING TO COMMUNICATE WITH THEIR HEALTH CARE PROVIDER (2014)

96% OF NON-FEDERAL ACUTE CARE HOSPITALS POSSESSED CERTIFIED HEALTH IT USING DATA

50% INCREASE IN HOSPITALS ROUTINELY NOTIFYING A PATIENT’S PRIMARY CARE PROVIDER UPON HIS ENTRY TO THE EMERGENCY DEPARTMENT

STUDENT PROFILE

VICTORIA TIASE

Age: 45
Hometown: Manhattan, New York City, NY
Education: BSN, University of Virginia; MSN, Columbia University; 2nd-year PhD student, University of Utah
Work: Director of Research Science, New York-Presbyterian Hospital
Family: Husband Lowell, a reinsurance actuary
Mentors: Dr. Mollie Cummins, Dr. Katherine Sward
Career Goal: Maximizing the use of health data to provide a deeper understanding of the patient and create efficiencies, improve outcomes and provide quality care
Latest Publication: Studying use of an app to document patient medications, “Assessing Impressions of Community Health Worker Use of Tablet-Based Medication Documentation Software,” Computers, Informatics, Nursing, September 2017

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adverse birth outcomes to either mom or baby, I will feel like I’m making an impact that could transform the lives of the childbearing family.

Researcher Dr. Gwen Latendresse, PhD, RN an associate professor at the college, also is focused on empowering new mothers and helping them navigate postpartum depression. Using a grant from the Utah Department of Health, Dr. Latendresse has developed a telehealth model for early screening and group therapy in rural areas. The women “meet” remotely for eight weeks in a video conference with a facilitator—usually a psychiatric/mental health nurse practitioner.

“The technology is key,” Dr. Latendresse says. “The women say, ‘If I had to get out and get in my car and go someplace, I would not have done this.’ They don’t have to leave their homes. That can be a huge barrier.”

Lisa Taylor-Swanson, PhD, an assistant professor, studies the use of traditional East Asian medicine interventions—including acupuncture, Chinese herbal medicine and moxibustion—on midlife women’s health, chemotherapy symptoms and cancer pain. And Mardie Clayton, PhD, associate professor, focuses her research on optimizing communication between breast cancer survivors and their providers, as well as teaching nursing PhD students to apply ethical standards during communication with study participants.

Several College of Nursing faculty members have focused their research on understanding—and alleviating—health disparities among minority women. Piles of immunization data preserved by the National Center for Health Statistics and the Utah Department of Health may provide answers to explain differences in HPV vaccination rates and cancer risks for vulnerable populations. Using these immunization datasets and grants from the National Cancer Institute, Deanna Kepka, PhD, an assistant professor at the college of nursing, also studies immunization rates for childhood cancer survivors. Ultimately, Kepka’s goal is to improve the quality of primary healthcare services and cancer prevention for low income, rural, and Latino populations.
“It’s a really wide lens,” Dr. Kepka says. “We’re trying to understand the contextual factors related to missed opportunities. We have this cancer-preventing vaccine that is severely under-utilized. Why are teenagers getting all the other vaccines, but not HPV?”

At the same time, a team of researchers and community health workers – or promotoras – gathered by Ana Sanchez-Birkhead, PhD, associate professor, are developing bilingual technological and personal interventions to empower Latina breast cancer patients with self-management skills and cancer care support at home. Dr. Sanchez-Birkhead says the National Cancer Institute-funded project has built trusting relationships between the community health workers and her patients.

“Many of these women face language, literacy, economic, social and cultural barriers that affect their quality of life and long-term health outcomes,” she adds. “Technologically-driven interventions that offer education and support and reach Latinas where they live can reduce breast cancer survivorship disparities.”

Community health workers also feature prominently in the research of Sara Simmons, PhD, RN, an associate professor at the college. Dr. Simonsen has geared her “participatory research” toward addressing health disparities among the women of Utah’s ethnic groups, enlisting the help of Community Faces of Utah and others to identify research topics, implement interventions and share the results. Her research, funded with grants from the U.S. Department of Health and Human Services’ Office on Women’s Health, created a bottom-up wellness coaching model to combat obesity. Now, she’s working on a study to explore using the same model to help prevent unintended pregnancy and promote preconception care with funding from the March of Dimes.

“We know that asking a simple question can make a huge difference in determining a health strategy,” Dr. Simonsen says. “For example, if you ask a young woman, ‘Would you like to become pregnant in the next year?’ How she answers enables us to help her either prepare for a healthy pregnancy or prevent an unwanted pregnancy. But she may answer a clinician differently than she would a trusted person from her community. That’s something I’m interested in.

“People from the community are truly our partners in every sense.”

Addressing Women’s Health

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TOTAL ENROLLED
STUDENTS
373 BACCALAUREATE
46 MASTERS
290 DOCTOR OF NURSING PRACTICE
46 PHD

TOTAL GRANT PORTFOLIO
$27 MILLION

FUNDING
$2 MILLION IN DONOR FUNDING
$1 MILLION IN STUDENT TRAINSHIPS, SCHOLARSHIPS, FELLOWSHIPS
7 ENDOVED CHAIRS

FACULTY PRACTICE
2019 U.S. NEWS & WORLD REPORT RANKINGS OF BEST GRADUATE SCHOOLS
#6 NURSING INFORMATICS SPECIALTY TRACK
#9 NURSES NURSERY SPECIAL TRACK
#19 DOCTOR OF NURSING PRACTICE
#30 COLLEGE OF NURSING GRADUATE PROGRAMS