THE NIH CAREGIVING STUDY NEWSLETTER

April 2020

Welcome

The Caregiving Study Team would like to extend our sincere thanks to you for your involvement in this study. As we have said in years past, understanding the caregiver experience is a priority research area for the NIH, and we feel privileged to be working with you in this endeavor!

We have learned a lot from you – and hope that, as we share what we have learned with the scientific community, we can play an important role in addressing some of the challenges and opportunities that you have expressed. For example, we are just finalizing a paper that investigates patterns of health and social service utilization and perceived barriers to utilization for children and families with inborn errors of metabolism. We hope that this work will inform policy that helps families navigate the system and access available resources.

2019 has been a busy year for us! The word about the project has gotten out and has resulted in two new collaborations. We are now partnering with families caring for a loved one affected by Batten's Disease and Leigh's Syndrome. A warm welcome to the study! This expansion will provide opportunity for us to identify aspects of the caregiving experience that are similar across contexts, as well as aspects that are unique to a given context – with the ultimate goal of translating our findings into interventions and policies that help you and families with similar challenges.

Finally, in 2020, we hope to move our protocol into a longitudinal effort. With the continued effort to identify potential treatment pathways for many of the conditions affecting relatives of our participants, we will investigate how caregiving roles and experiences shift across treatment course or as families age.

Laura Koehly, Ph.D.
Principal Investigator

Particpants in the Caregiving Study

The Caregiving Study has been in progress for the past four years. In this time, we've had families come from across the US (and other countries) to participate in our study. These families include those with children with rare genetic conditions or undiagnosed conditions, as well as families with children without a chronic medical condition.

Through in depth interviews with all of you, our team has gained much insight into what it means to be a caregiver. This figure shows the breakdown of our participants by how they define their relationship to the care participant.

Pie chart: Other, 3.60%; Other Family, 11.40%; Grandparent, 13%; Mother, 44.60%; Father, 27.40%
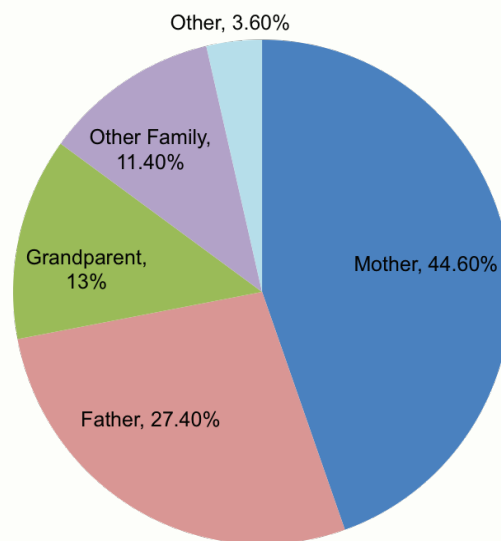
THE FUTURE OF THE CAREGIVING STUDY

We are making some changes to our study in 2020. Most notably, we are transitioning our interview to a life history style interview, and adding a longitudinal component to the Caregiving Study. Below, Drs. Jasmine Manalel and Dawn Lea discuss the implications of these changes.

Life History Q&A with Dr. Jasmine Manalel

What is a life history interview, and how is it different from the open ended interview style that we've used previously?

Broadly speaking, a life history interview is a way to link past events and experiences to current-day experiences or outcomes. For example, you might be able to link early life educational experiences with occupation or income in adulthood. Life history interviews have roots in anthropology and are currently used in many different fields of study. A life history interview can span several content areas, including residential, educational, occupational, partnership, and health history, or they can be more focused. Our study, for example, focuses on caregiving history. I think the main difference from the open-ended interview style is that we are explicitly asking about caregivers' most salient past experiences as a caregiver.

What kind of information are you hoping to capture through the life history interview that is currently missing from our research?

As with any life history technique, we are trying to understand the past and present contextual factors that influence current caregiving experiences. We want to know if and how those salient past caregiving experiences shape the current (and anticipated future) experience and identity as a caregiver.

Can you tell me a little bit about how you would like to see this work translate into real help for the families in our study?

I hope that clinicians and policymakers will be able to take our findings and translate them into help at multiple levels, like optimizing strategies for individuals and families to cope with caregiving stress and also implementing structural change to create a society or system that better supports caregivers and their families. That's why we work so hard to get our findings out into the world - by presenting at conferences and publishing academic papers. Interdisciplinary team science is also so important, so that we can address challenges from multiple points.

You've been part of the Caregiving Study for 1.5 years now… What about this research excites you and keeps you here?

I'm a lifespan developmental psychologist by training and the Caregiving Study incorporates all my favorite things about the field. It is multigenerational and it takes a lifespan and life course approach. It's very exciting and rewarding to put all my training to use in such a meaningful way.

Lastly, is there anything that you'd like to say to anyone who might be reading this?

Just thank you - we acknowledge that contributing to this study might be time consuming and we appreciate all our study participants and their families for their dedication and (hopefully) continued participation!

Longitudinal study Q&A With Dr. Dawn Lea

How is a longitudinal study different from a cross-sectional study?

The Caregiving Networks Across Disease Context and the Life Course: A Comparative Longitudinal Study (aka The Longitudinal Caregiving Study) will recruit caregivers 18 years and older who provide assistance to a person with a chronic condition that requires medical, physical, or mental support. We plan to follow family caregivers for many years to assess the caregiver's health and social support systems because caregiving processes vary across types of illnesses over time. This Longitudinal Caregiving Study will follow research participants over a period of time, whereas our current Caregiving Study is a cross-sectional study and collects information at a specific point in time.

We are in the developmental phase of the Longitudinal Caregiving Study. In this new study, we plan to conduct a brief data gathering "visit" by email on a quarterly basis and annually we plan to conduct a survey and an interview, similar to the current Caregiving Study. We'd like to collect blood and/or saliva specimens to study the effect of stress over a long period of time but it is not required for participation in the study. For some caregivers and individuals who may never come to the NIH, we hope to be able to conduct the entire study without an onsite visit to the NIH.

What are you hoping to learn about through the longitudinal study that is currently missing from our research?

We are hoping to tell the story of caregiving over a long period of time – how caregivers cope, their social networks, support, stress, and sometimes the bereavement process (if their loved one passes away).

Can you tell me a little bit about how you would like to see this work translate into real help for the families in our study?

If we can determine the most stressful times and events for a caregiver we may be able to figure out how best to assist families through the most trying times in their caregiving.

You've been part of the Caregiving Study for 3 years now… What about this research excites you and keeps you here?

I have been involved in research for many years and my personal mantra has always been "Research Changes Practice". As a clinician, I strive to improve communications and care of patients and families. I love to get the caregiver's perspective about what they're doing to manage anything related to taking care of their family member, what works for them, and what information they want to share with the research team. By gathering this information, we can collectively analyze the responses and share with others "best practices" and generate "evidence-based practice" for patients and providers across various specialties.

The longitudinal aspect of the study is in the process of being finalized. For more information, please contact us at CaregivingStudy@mail.nih.gov.

MEET THE RESEARCH TEAM

The NIH Caregiving Study is run by team of post-baccalaureate fellows, post-doctoral fellows, staff scientists and clinicians. We feel grateful to be working with people and families such as you and yours and we thank you for making this study possible.

Every year the study team makes holiday themed gnomes for the children at the Children's Inn as an ongoing gesture of gratitude and support.

Top: (left to right) Dawn Lea, Mindy Perilla, Tracy Swan, Anna Shetler, Maddy Granovetter, Laura Koehy.
Bottom: (left to right) Hannah Davidson, Sydney Sumrall, Meghan Grewal, Chris Marcum.

Laura Koehly, PhD.
Dr. Koehly heads the lab. Her background is in Psychology, with an expertise in family systems. Her research aims to identify pathways for intervention to help families communicate about and adapt to inherited disease risk. Dr. Koehly is a "military brat" who has landed in Maryland. She is married with two adult children and two grandchildren.

Mindy Perilla, MPH CCRC.
Mindy is a certified clinical research coordinator and the lab's Project Coordinator. She works on study documentation, regulatory processes, and data management. Mindy was a participant in clinical trials (phase 2,3) before getting involved in research professionally, and feels those experiences informed the perspective she brings to her work today. She is a self-described "public health geek," interested in all sorts of global health issues.

Hannah Davidson, BA.
Hannah is a post-baccalaureate fellow in Dr. Koehly's lab. She is involved in qualitative data analysis/coding, interviewing participants, and lab work. She is interested in how people grow and make positive meaning through the caregiving experience. When she is not at work, Hannah volunteers as a doula and harm reduction outreach volunteer for community health organizations in DC. She loves going to weekly farmers markets, hiking the amazing trails around the DC area, and making art.

Tracy Swan, BA.
Tracy is a post-baccalaureate fellow in the lab. She is working on a project investigating the methylation patterns in stress-related genes of caregivers. Eventually, she will correlate these patterns to caregivers' survey data describing social support to better understand their biopsychosocial well-being. As an undergraduate, Tracy studied biology and public health. She enjoys cooking recipes from the New York Times.

Christopher Steven Marcum, PhD.
Dr. Marcum is a staff scientist in the lab. His research focuses on statistical methodology and how health and aging shape interpersonal processes over the life course. He enjoys spending time outdoors with his family and pooches on the weekends.

Dawn Lea, PhD, MSN.
Dr. Lea is a nurse scientist in the lab. Her research aims to investigate predictors of outcomes in community dwelling individuals affected by chronic diseases; specifically, the role of caregivers and how the social and familial system influence health outcomes.

Anna Shetler, BA.
As a post-baccalaureate fellow, Anna enrolls and interviews participants, and helps manage the study data. In undergrad at Goshen College, Anna studied biology, chemistry, and psychology. She will be starting graduate school in the fall, focusing on geography and health disparities. Anna loves to cook, play with her cat, and explore new places.

Meghan Grewal, BA.
Meghan is a post-baccalaureate fellow in the lab. She is involved with participant-facing tasks, as well as running experiments on biological specimens. She is interested in understanding how social support can mitigate biological stress responses and improve health outcomes in caregivers. At Scripps College, Meghan studied biophysics and economics and she will be applying to medical school in the fall.

Jasmine Manalel, PhD.
Dr. Manalel is a postdoctoral fellow in the lab. Her background is in developmental psychology. Her research focuses on how close, social ties are linked to health and psychological wellbeing across the lifespan. She loves group fitness, going on nature walks, and traveling to new places.

Megan Cooper, MSW.
Megan is the clinical research coordinator for the Caregiving Study. She is a Licensed Clinical Social Worker with a background in working in crisis intervention, substance abuse, and inpatient mental health settings. Outside of work, Megan stays busy by planning her upcoming wedding and keeping up with her six year old son.

Maddy Granovetter, BA.
Maddy is a post-baccalaureate fellow in Dr. Koehly's lab, and enjoys conducting interviews, coding, and processing biological samples. Her research projects focus on the caregiving and support roles of siblings, and biological markers of caregiving-related stress. Before joining the lab, she studied molecular and cellular biology as an undergraduate. She also loves reading, running, and theater.

Sydney Sumrall, BA.
Sydney is a post-baccalaureate fellow in Dr. Koehly's lab. She is working on projects such as the measurement of interpersonal stressors and the utilization of coping strategies among caregivers. She interviews participants and cleans data in preparation for analyses. At Emory University, Sydney studied psychology, and she plans to apply to clinical psychology graduate programs in the fall. She loves running outside and cooking healthy food.

If you have any questions about the study, please contact us at CaregivingStudy@mail.nih.gov.