The Center for Clinical Outcomes Development & Application (CODA) at the University of Michigan is leading a multi-site study, HDQLIFE, to identify important issues associated with health-related quality of life for individuals living with Huntington disease (HD).

While questionnaires (measures) exist to assess health-related quality of life (HRQOL), they were not developed specifically for people with HD and therefore, they often do not cover all of the relevant aspects for individuals with HD.

The purpose of this study is to develop a brief, valid and reliable measure of quality of life for HD that can be used to determine the effectiveness of treatments in improving quality of life.

In addition to developing and validating a new measure of HRQOL in HD, the HDQLIFE study is attempting to extend the PROMIS and Neuro-QOL measurement systems, which were developed by Dr. David Cella and colleagues and funded by the NIH. The PROMIS project developed a comprehensive system of generic item banks for use in chronic disease populations. Neuro-QOL focuses on neurological disorders, including movement disorders. Although the Neuro-QOL system is focused on neurological disorders, it does not cover some of the more unique aspects of HD. To remedy this, the HDQLIFE study has developed three new questionnaires that focus on chorea, speech and swallowing difficulties, and end of life issues. Once the study is completed, these measures will be easily accessible to clinicians and researchers focusing on HD.

In addition to adding these new measures, the HDQLIFE study is also working to evaluate existing measures in the PROMIS and Neuro-QOL systems for use in HD. These existing measures focus on many different aspects of quality of life, including physical/functional, mental and social. This will greatly expand the reach of the Neuro-QOL and PROMIS systems to the whole spectrum of HD, including the pre-symptomatic and early stages.

Meet the Principal Investigator of HDQLIFE

Noelle E. Carlozzi, Ph.D.,
Director, Center for Clinical Outcomes Development & Application (CODA)

Dr. Noelle Carlozzi is an Assistant Professor in the Department of Physical Medicine & Rehabilitation and Director of the Center for Clinical Outcomes Development & Application (CODA) at the University of Michigan. She is currently the principal investigator of two large NIH grants, including HDQLIFE. The other project, TBI-CareQOL, addresses quality of life of caregivers of individuals with traumatic brain injuries.

Dr. Carlozzi first began working with individuals with Huntington disease during her fellowship at Indiana University where she worked on the PREDICT-HD Study. After leaving Indiana, Dr. Carlozzi pursued additional funding to continue doing research with HD.

Dr. Carlozzi has a strong passion for improving the quality of life in individuals suffering from chronic illness, as well as their families. Her experience allows her to do so by developing better ways of measuring it.

“Commonly used HD measures are typically not comprehensive and do not account for clinically meaningful changes in functioning... This greatly limits the ability of the research community to evaluate outcomes that are most important to HD patients.”

Without being able to measure these outcomes, the process of researching and developing new treatments to improve them becomes much more difficult.

To address this issue, Dr. Carlozzi combined her interest in Huntington disease with her measurement expertise to begin work on the HDQLIFE pilot study in 2009. The success of this pilot study laid the groundwork for the HDQLIFE Study.
Dr. Dayalu's first encounter with Huntington disease (HD) occurred during the first year of his residency. When asked what interested him most about HD, Dr. Dayalu responded, “I can't say which [aspect] of the disease doesn’t interest me...it’s a unique kind of genetic mutation that only a few diseases share. The fact that it has complex effects on the brain that can be subdivided into behavioral, motor, and cognitive makes it very interesting to study.”

Now having spent close to a decade treating HD patients, Dr. Dayalu has learned much about the disease and the significant impact it has on patients and their families. “It often strikes patients at the prime of their life...they’ve got families...there are issues like genetic testing...questions like ‘what’s going to happen to my kids?’ Being able to intervene and help at this point makes it a great place to be if you’re a clinician interested in the human condition.”

Dr. Dayalu finds his work very fulfilling and satisfying. “HD is such a devastating disease and yet, in some ways, it’s treatable. We can’t slow it down or cure it yet, but there are many things we can do to really improve a patient’s quality of life.” This has a lot to do with a shift, within the last decade, in how clinicians approach the treatment of HD. “There is a large awareness now of the behavioral and psychiatric elements of HD. For many years, probably decades, people thought of HD as a disease of chorea, and the reality is that a minority of patients actually cite chorea as their biggest problem, a very small minority.” With this realization, trainees are now taught to focus more on the emotional and behavioral aspects, taking into account the person’s mood and emotional state.

In addition to our participating sites, the HDQLIFE team is traveling to HDSA chapters, support groups and nursing homes across the country. This past year, the UM and University of Iowa study teams traveled to Lansing, MI for an HDSA Hope Walk. Here, seven individuals completed the HDQLIFE study on site. The team also made a trip to JFK Hartwyck nursing home in Plainfield, New Jersey. The home specializes in the long term care of late stage HD patients. The facility, directed by Kathy Little, is one of only a handful of recognized long-term care facilities in the country dedicated to Huntington disease. The team spent two days working with six of the residents to complete the HDQLIFE study.

We are able to travel to different locations and bring the HDQLIFE study directly to participants. If you or anyone you know is interested in participating, please contact the study team.

Since seeing our first participant in December 2012, more than 350 participants have enrolled in the study across all of our sites!
HDQLIFE Team Takes a Trip to the Movies

The HDQLIFE team has worked closely with the Huntington's Disease Society of America (HDSA) to help raise awareness for HD and also to inform individuals about HD research that is being conducted. From visiting support groups to attending state and national conventions, HDSA has been instrumental in spreading the word about HDQLIFE and other HD studies.

The HDQLIFE team recently joined Michigan's HDSA chapter in Holland and Canton, MI to view the new HD documentary, ALIVE & WELL, and to inform people in attendance about HD research being conducted at the University of Michigan.

ALIVE & WELL is a powerful documentary film about the human condition, which follows seven resilient people coming to terms with the profound reality of living with the hereditary chronic illness known as Huntington's Disease (HD). Far from giving us a hopeless glimpse into life with terminal illness, ALIVE & WELL reminds us all of our ability to persevere with strength, despite life's most difficult challenges.

HD Patient’s Visit to the Big House

This past fall, while attending an HD walk in Lansing, MI, we had the opportunity to meet with the Johnson family. John and his daughter, Kimmy, have both been diagnosed with Huntington disease. After talking with them at the walk, we discovered that they were huge fans of the Wolverines. With this in mind, we went to Michigan’s Athletic Department who were more than happy to arrange for a private tour of the Big House for John and his family.

On a chilly afternoon in October, John and his family packed into their cars and drove down to Michigan Stadium where we met with Don Svenson of the Athletic Department. Don took John and his family through the private suites, showed them the trophy cases, and even brought them down the tunnel to the 50 yard line. “John watched his family members run from end zone to end zone and act silly enjoying themselves,” recalled Becky Johnson, Kimmy’s mother.

“It’s a blessing to be able to use football to reach out to families such as the Johnsons”

-Drew Dileo #9

But that wasn’t all. The surprise at the end was a tour of the locker room where John and his family got a chance to meet Drew Dileo (#9), Graham Glasgow (#61) and Ryan Glasgow (#96) of the Michigan football team. Becky remembers John and Kimmy’s reactions when they first stepped into the room. “Kimberly was in tears and John was all smiles.”

Dileo and the Glasgow brothers were just as happy as the Johnsons to be able to be there that day. It was an incredible experience for everyone involved. All the players, members of the athletic department, and study team who were there felt thankful for the opportunity to give the Johnson family a moment when they could just enjoy themselves and each other. Kimmy and Becky said, “This is something our family will always remember!” Thank you to the Athletic Department and the Johnson family for letting us be a part of this very memorable day!
CODA Research Registry

The purpose of the registry is to keep the names and contact information of people who would like to hear about our future studies at the University of Michigan. This will allow us to contact you if you or your child might be eligible to participate in a new research study that we are conducting.

If you join the CODA registry, we will collect basic information from you, such as your birth date, race, gender, and contact information, as well as your medical diagnosis, if applicable. This information will be used to see if you are a good fit for a future study.

By joining this registry, you will have the opportunity to participate in studies that you may not otherwise learn about.

To learn more about being on the CODA registry, please contact the CODA study team at 734-764-0644 or via email at PMR-CODA-Lab@med.umich.edu.

Editor’s Note

My name is Nick Migliore and I am the coordinator for the HDQLIFE study at the University of Michigan (UM). I have had the pleasure of working with all of the study participants at UM and their families. This experience has given me the opportunity to hear the stories of more than 70 families suffering from the effects of Huntington disease.

My first reaction to these stories was shock. How had I gone this long not knowing what HD was? Why is no one talking about this? Ruth Lentner, a long-time HD advocate and supporter throughout the state of Michigan, told me, “It’s one of the worst diseases out there that almost no one knows about.” I couldn’t agree with her more.

One of the things I find most interesting about my experiences was how unique each story was. Although there are many similarities, each family’s situation differed significantly. Even within a family, I was surprised at the differences in the progression of the disease among siblings or between a parent and their child.

Although it has been an incredible two years here at UM, my involvement with the HDQLIFE study will sadly be coming to an end this summer as I prepare to go off to graduate school. I would like to thank Dr. Carlozzi for allowing me to be a part of this project. It has been an incredible learning experience.

I would also like to thank the Michigan HDSA chapter for allowing me to become a part of their family. It has been a blessing to be involved with such a great organization. I will not forget the experiences I’ve had here, and the stories I’ve heard. My involvement with this project will end, but my involvement with the HD community will not. I will continue to spread the word to as many individuals as I can. As I’ve told many people before, “All it takes is one HD story, and you’re hooked!”

-Nick Migliore, Editor
migliore@med.umich.edu

If you have questions or want to learn more about the HDQLIFE study, please contact us:

Phone 734-764-0644
Email PMR-HDStudy@med.umich.edu
Web med.umich.edu/CODA/HDQLIFE

HDQLIFE is a research study conducted by the University of Michigan Medical School, sponsored by the NIH-NINDS and in partnership with PROMIS® & Neuro-QOL
Award #: R01NS077946, HUM#: 00055669