



Let's Talk: Measuring QOL in ND

Wednesday, July 21, 2021 (11:30 am – 12:30 pm ET)

Adira Foundation invited a diverse group of professional stakeholders interested in measuring quality-of-life (QOL) in people most impacted by neurodegenerative diseases (ND) to join us in a discussion exploring the landscape of existing QOL assessment tools and the value of creating a common standard to measure QOL in ND on a broad scale.

At the event, we:

- Presented findings from our report which analyzed 50 existing QOL assessment tools
- Provided recommendations to create a common standard of QOL metrics
- Provided recommendations to create a shared evaluation process across ND stakeholders to assess QOL impact in ND on a broad, systems-wide scale
- Gathered insights and comments from professional ND stakeholders on the purpose, practicality, and practices of measuring QOL in ND groups

Report Presentation

An introduction and overview of the full report was presented at this event and is summarized here. A full transcript of the presentation is included with the event slides.

We invite you to access and comment on the full report and the assessment tool library at www.adirafoundation.org/inform-qol

- Adira analyzed 50 assessment tools commonly used today to evaluate QOL
 - Tools designed for use in general populations
 - Tools designed for use in people living with an ND, including Alzheimer's disease and related dementias, ALS, Huntington's disease, multiple sclerosis, and Parkinson's disease
 - Tools designed for use in caregivers
- An assessment tool library was created to better understand the current landscape of QOL measures (what is being measured, how, in which populations, etc.)
- The analysis found existing assessment tools to evaluate QOL focus on measuring specific factors affecting QOL outcomes, not QOL measures themselves
- We developed a common standard to measure QOL in ND that focuses on what matters most to people impacted by ND. These measures were distilled from a combination of the report analysis and our direct listening activities with people



most impacted by ND to better understand their priorities, motivations, and needs.

Measuring QOL in ND

| | |
|------------|--|
| Time | More time to spend doing the things they enjoy |
| Money | More money in their pockets to live full lives |
| Energy | More physical and mental energy |
| Confidence | More confidence to navigate systems and make informed decisions |
| Connection | More opportunities for connection and feelings of shared community |

The 5 measures recommended by Adira as a common standard to evaluate QOL in ND

- We aligned the subscales and specific measures used in the 50 assessment tools we analyzed with the 5 QOL metrics we developed as a common standard.
 - We found strong alignment between the measures used in these tools to evaluate factors impacting QOL and the direct QOL measures of *time, money, energy, confidence, and connection.*

| The Parkinson’s Disease Questionnaire-39 (PDQ-39) measures... | These align with the Adira recommended QOL metric of ... |
|---|--|
| Difficulty walking, carrying bags | Energy |
| Feeling depressed, anxious | Energy |
| Feeling isolated, loneliness | Connection |

Example of metrics alignment between existing tool and recommended common standard





- In addition to the desire to measure what matters most, we selected 2 other critical features we believe to be important factors for an effective evaluation tool based on current best practices
 - The use of simple, plain language
 - Minimizing responder burden
- Two tools are highlighted in the report, one for evaluating people living with ND and another for evaluating ND caregivers. These tools align with 4 of the 5 measures of *time*, *money*, *energy*, *confidence*, and *connection*, use plain, simple language, and require minimal responder burden.
 - World Health Organization’s Disability Assessment Survey 2.0 (WHODAS 2.0)
 - Kingston Caregiver Stress Scale (KCSS)

Recommendations

1. Create a common standard to measure QOL in ND
2. Develop resources, including an interactive assessment tool library, to support the evaluation efforts of organizations interested in measuring QOL in ND
3. Implement a shared evaluation process across ND stakeholders to measure QOL impact on a broad scale

Create a common standard

- We look to test these 5 recommended measures of *time*, *money*, *energy*, *confidence*, and *connection* further in people most impacted by ND.

We need more people living with ND and ND caregivers to provide their perspective on these measures and to better understand how they prioritize these 5 in their own lives.

Develop resources to support QOL evaluation

We created the assessment tool library to help organizations interested in measuring QOL in people most impacted by ND to identify existing tools they can use that best align with their program goals and design.

- Search by tool name, subscales, QOL impact area, simple vs. complex language, length of assessment, etc.

The tool can be improved and expanded. We need feedback on how we can best do that. We encourage you to use the assessment tool library and let us know how we can improve its usability and application.

- We recommend the creation of a framework to describe the relationship between measures to evaluate factors affecting QOL and measures to evaluate QOL directly





- This framework can be used as a resource to help advance conversations on the value of measuring QOL in ND across stakeholders
- The framework can also be used to relate the unique needs of people most impacted by ND to a broad audience. Understanding these needs as universal, human desires can help to de-stigmatize the specific needs of people impacted by ND
- We look to collect feedback on the alignment of measures used in existing tools (factors affecting QOL) with the 5 recommended measures of *time, money, energy, confidence, and connection* (QOL)

Implement a shared evaluation process

- We recommend the creation of a translation tool to quantify outcomes from existing assessment tools as QOL outcomes in the areas of *time, money, energy, confidence, and connection*
 - With this tool, Adira hopes to collect and aggregate outcomes from a diverse set of ND stakeholders to show QOL impact on a broad scale
 - With this information, we can act as a collective to identify programs effectively impacting QOL in ND and target resources and funding to fill gaps in care and prioritize what matters most to people impacted by ND

We ask for contributions from a wide range of stakeholders to inform the design and development of this translational tool.

Comments and feedback on the report, assessment tool library, and recommendations can be sent to programs@adirafoundation.org

Breakout Sessions

Discussion 1: Purpose

Participants discussed shared identity and the universal, human concepts described in our common standard (*time, money, energy, confidence, and connection*).

Highlights

- Several applications of the value of measuring QOL in ND were identified and explored.
 - Capturing the immense QOL impact caregiving has on ND caregivers
 - “We provide resources and information for tens of millions of caregivers across the US. Not surprisingly, perhaps the largest cohort of people who use our help and resources are in our



caregivers with loved ones with neurological conditions, because that's where the caregiving challenge can be so strong. And we've always had a very strong sense of the great need for QOL measures for family caregivers in this space."

- Putting real, measurable data behind QOL impact
 - *"If we can get a handle on these measures, to really show the value of the work, instead of having to always just say anecdotally. Looking at kind of what is the impact and what is the outcome of what we do. I know, you know intuitively, and I know as a human being, that there is a human value, but how to you translate that? There's this basic purpose to prove to funders in government and policy people that it's good work and they should give us more money so that we can expand because it's going to take all of us to do this together."*
 - *"I have done a lot of thinking about QOL and how it changes for those individuals who are very early in the disease, to those who are profoundly disabled and cognitively impaired and need more assistance. But the potential for QOL is always there. And I think that's something that we should keep our eyes on and not be judgmental from our cognitively abled selves in some ways."*
- A shared identity, common amongst us all universally as humans, was discussed as a potentially definable concept
 - *"With QOL measures, with the family caregiver, it's definitely multivariate, so it isn't just you know, kind of your immediate level of stress or particular health condition, it really spans a fairly wide spectrum of things, including the financial burden, how you're relating in your social circle – but there's no questions, it's certainly the challenge, right? I mean, here we're looking at quality of life measures. It's kind of basically life itself."*
 - *"One value that we put forward for this is to help reduce stigma by suggesting that someone with any one particular disease has a particular special QOL conversation that is only unique to them and sort of puts them off to the side, but rather says, no, these experiences are common. There are just human issues."*
- The 5 measures of time, money, energy, confidence, and connection were reflected on. Some participants provided feedback on the specific language chosen to represent the 5 metrics.
 - *"Connection. Really, we're looking for that antonym of isolation. You know, there's fellowship and other things and social connections. I think*



of that connection as a community, and I think so much of what we do through our various programs is because, with many of these diseases, think the caregiver, especially the person with the disease, there is profound isolation (which has only been compounded by the pandemic and continues to be, by the way). That sense of community, when people are in a group, when people come to a meeting, people are connected. Even on the phone to a helpline dementia specialist, just that sense of being heard and understood and validated it immensely improves QOL.”

- Participants discussed the value of a common set of measures that can align information from multiple sources into one comprehensive picture
 - *“I work in psychometrics. I think it’s important to identify that there are different sources of information, the patient being one, the caregivers, the physician. So, I think there is a need to align with all sources of information to provide a comprehensive picture as opposed to one source of information, because it’s always limited how a person can do and it may not tie up to that person’s overall quality-of-life.”*
- The value of evaluating QOL impact on a broad scale was discussed, specifically the value of comparing and being able to show QOL impact across various program types. These types of insights could be used to inform decision-making to better target funding and programs for people most impacted by ND.
 - *“It’s this whole spectrum of things that we do and try to measure. I think of this in the dementia space, family caregivers will hear a lot about memory loss. They won’t necessarily hear a lot about what we would call agitation and aggression. And the very idea that we kind of tell them a little bit more simply about agitation, delusions, hallucinations, itself improves their quality of life and reduces their stress. It’s not just these things that may be kind of sophisticated with four steps, but some of these things that we can do that are you know, much more straightforward.”*
 - *“If you implement a particular intervention, how much is that going to change the QOL (a number, a change in a point scale). If you can show that and compare that you can identify and implement what works.”*
- The concept of ‘response shift theory’ was discussed and how this may impact the reliability of scales used in measurement today
 - *“Considering scales and how things are being asked in their measurement is very important. A pain scale of 1 to 10 is going to be perceived by people with different experiences very differently. And based on a catalyst, an event, an experience, even an individual’s perception of that scale can change over time. Take for example a woman expressing pain for a fractured ankle on a pain scale of 1 to 10. Before experiencing pregnancy, they may rate that pain a 7 or 8, but even the*

same person, having going through an experience like pregnancy, may later rate that same pain as a 2 or 3. It can happen with other scales too, like asking if someone can walk a block or a mile, when their perceptions of those distances may vary.”

- Immediate reactions to the tools highlighted in our report analysis support our theory that existing metrics to measure factors impacting QOL can be effectively aligned with the 5 metrics identified in our common standard
 - *“One of the things I was very pleased about at the beginning of the presentation today, the Kingston scale really does get at sort of more basic parts of what goes into quality of life for family caregivers.”*

Discussion 2: Practicalities

Participants discussed QOL evaluation challenges and explored the types of resources and tools that could help improve evaluation processes.

Highlights

- Participants discussed some of the primary challenges they have faced as an organization evaluating their programs and QOL impact
 - Expanding their outreach to hear from more people
 - *“I’m with a national Parkinson’s organization, we cover the US and we actually have been doing these evaluations both locally and online for at least the last 6 years. It’s just so hard to know that you’re reaching everyone. We know we’re reaching everybody who’s online because we get huge online response every year. We have tried doing handwritten or distributing through clinical centers, etc., but we do get a very small response from people who we think are not connected online or maybe would be more inclined to write out a response for survey information. I think it’s challenging just to know that you’re reaching everybody who wants to talk to you about this so you’re addressing what their QOL issues are.”*
 - *“I think there are systemic biases. Who responds online, who has access to online. How is that offered in language of choice or use of imagery for those who may have challenges with written language.”*
 - *“Stigma. In a number of populations stigma might affect how somebody is completing a survey or how someone might even see a survey as unattractive simply because it means you actually have to address something that’s going on. It might be very private to you or to your family based on certain cultural context.”*



- Knowing how to choose the right respondent
 - *“In our center here in Williamsburg, VA, we’re particularly focused on serving patients living with memory loss and their family caregivers or care partners. If the person with memory loss has progressed enough that they can’t respond on their own to a QOL tool or answer interview questions, is the caregiver, their family caregiver the best proxy for them? And if so, what are the best tools for proxy-response use in QOL measurement?”*
- Reaching out in ways that connect with the respondent’s needs
 - *“There’s been a little bit of quietness to our population recently because there has been some disappointing research news, so people have taken a step back. And then on top of that, with COVID, our response rate has decreased a little bit with just general engagement, so other things, those things can compound finding the right tool or approach to reach out.”*
 - *“One area with online engagement is fraud and abuse. Older adults and people impacted by an ND are sadly targets. So, how to make respondents feel confident that by responding to whatever they’re being asked to respond to electronically it’s not going to lead down a path to have a very deleterious impact on life in other ways. I think that’s a challenge.”*
 - *“I’m sure a lot of you can appreciate this, one challenge is that time doesn’t really mean anything in the end because, as the creator of the survey you can think it might take 5 minutes, but for someone with Parkinson’s who has difficulty with a keyboard or pen that can turn into 25 minutes very easily. We try really hard to fairly state that it’s about a number of questions rather than ‘this will take you 10 minutes’”.*
- We heard several creative strategies for overcoming outreach and response challenges that have proven effective for some organizations
 - Minimizing responder burden
 - *“We’ve really tried to condense and shorten the questionnaires that we use. That’s been a continuing challenge for us, there’s so much we want to know. Yet, we realize when people are filling out these forms, you know, anything that takes longer than 5 to 10 minutes, it’s just not likely to get filled out.”*
 - *“In terms of comprehensiveness, one thing we thought about is actually breaking up the survey into several parts. For example, if we had something that we might conceive of as 30 questions,*

actually doing that as a 2 or 3 part over a period of a few weeks or even months as a way of making it more manageable for people. That's something that has worked pretty well because it gave me only 10 questions rather than opening the survey and seeing 30 questions."

- Nurturing a deeper motivation to respond
 - *"Since we offer these programs free of charge, reminding people that one of things that enables that to happen is that funders are judging the data that we're giving and some of that data is related to surveys we're sending out. We don't expect anyone to pay for programming, but we do hope that they will contribute through these sort of survey collections, because that is in essence our funding source, and we remind them of that. That does seem to help in terms of incentive to want to support something very meaningful and supportive for them."*
- Exploring creative communication methods
 - *"Iconic or symbolic response as opposed to words, that's been an effective approach for us in trying to do as many questions as we can. Using icons to express mood, or you know, thumbs up / thumbs down, rather than long text questions."*
- Key areas were identified as those needing more focus, research, or resources to help advance QOL evaluation
 - Health equity issues, particularly translation and cultural interpretations of existing assessment tools
 - *"I think we're missing a lot of the input and a lot of key points because these surveys, either they're not already translated or the organization's distributing them don't have the resources to get that translation done."*
 - *"Sometimes, it's even more than just translation, it's cultural interpretation. Translating it into the language, you know, that doesn't address the cultural factors that oftentimes influence the questions or the type of information you're looking to gather."*
 - The use of positive versus negative (deficit) language in tools
 - *"A standard Parkinson's measure, PDQ-39, there's some real challenges with that particular questionnaire, not only in terms of length, but it tests to measure in terms of deficit. We found that when we ran a study of PDQ-39 versus open ended QOL questions, the open-ended responses were very positive – 'this program has*

changed my life’, ‘I can do this. I can do this.’, My mood is improved.’ – but compare that to the PDQ-39, there was a flatline, it showed no impact because it wasn’t picking up on those changes.”

- *“I think it’s better to have a strength-based kind of modality. And I think oftentimes that is an area that is lacking in the approach that’s taken to some of the QOL based surveys.”*

Discussion 3: Practices

Participants discussed ideas for how to best approach implementing our recommendations of a common standard and a shared evaluation process

Highlights

- Participants recommended additional features for the assessment tool library to better match organizations with the evaluation tools best meeting their needs
 - Identifying tools that use person-centered, positive language
 - *“Consider the specific use of language and terms use in the assessment tool, not just the simplicity or the complexity of the language. For example, caregiver burden is a common term used. It’s in the title of some surveys, and then in the questions this concept of burden is repeated throughout and that can be problematic for caregivers and really give the wrong message.”*
 - *“There’s a lot of talk about person-centered language and just making sure that we’re focusing on using those terms and phrases that focus on the individual themselves.”*
 - Categorizing plain versus complex language in even more specific terms, like literacy levels
 - *“Our biggest problem is always literacy. We have a wide range where we’re in a college town, but more than 30 percent of the population is below the poverty line, and many haven’t graduated high school. I struggle with validity across that wide gulf of education and language.”*
 - *“We try to keep our materials at a 4th or 5th grade reading level and we’ve gotten positive response not only from consumers but just professionals that work with these audiences that it’s helpful.”*
 - Identifying the cultural application of assessment tool measures
 - *“When looking at instruments, really looking beyond whether they’ve been translated. But do they culturally apply? What does that really look like? Because we’ve seen in some evaluation tools*

where it's been translated but the concepts don't apply in the same way. They don't have the same meanings, they're just not as relevant."

- Suggestions were made on how we might consider our approach to implementing a shared evaluation process across stakeholders
 - *"Look carefully at the scale for what you are recommending to basically standardize it. Some rating scales aren't going to be sensitive enough, so you don't end up seeing any change on this large scale because it's not sensitive enough to capture it."*
 - *"In aggregating outcomes, you can create something like a Z score, you put the scores on a common distribution and deviation and then you can convert each, so they have the same weight."*
 - *"Make sure you're thinking about the accessibility of the tool and the forms. Can it be administered or used digitally? Will there need to be a particular familiarity with the forms to complete them?"*
- The 5 measures of time, money, energy, confidence, and connection were reflected on.
 - *"Confidence. I was just thinking that we found the stigma from an ND, especially with Parkinson's disease because it can be visible, that can affect confidence and whether they would seek care. It seems like an intertwined concept."*

Takeaways

- More feedback from people most impacted by ND is needed to define the common standard
 - We need to further test these 5 recommended measures for QOL, *time, money, energy, confidence, and connection* in people most impacted by ND
 - Are these the right terms to describe these concepts?
 - Have we accurately aligned the factors affecting QOL with these 5 QOL measures? (*i.e., reducing insomnia → energy*)
 - How do people most impacted by ND prioritize these areas of QOL?
- The next iteration of this research will benefit from more conversation and collaboration with ND stakeholders
 - There are several ways we can enhance the assessment tool library to better match organizations evaluating QOL with tools that best meet their needs





- Describe more features of assessment tools that are important to evaluators
 - Specific literacy level of tool
 - Translated language options
 - Cultural interpretations and applications of tool
 - Specific language used in tool is person-centered
- Building a shared evaluation process to show QOL impact in ND on a broad scale has inherent value for individuals, programs, and systems but will require a focused, strategic effort to implement
 - We seek collaborators to take this work further and to explore with us considerations such as
 - How to quantify outcomes from the various scales used across assessment tools to one aggregated, standardized scale of measurement
 - How to develop a translational tool that is accessible, easy-to-use, and communicates outcomes in clear terms of QOL impact
 - How to most widely distribute these tools and resources to engage more ND stakeholders in this collective effort

Next Steps

Tell us more about your thoughts on the 5 common measures for QOL in ND of *time*, *money*, *energy*, *confidence*, and *connection* and how you evaluate QOL in your day-to-day work.

- Take a survey here - <https://www.surveymonkey.com/r/ZTL6TZN>

Share your critical comments, thoughts, and insights on the QOL event, report, and assessment tool library. We are eager to hear your feedback and connect again.

- Send feedback to Lauren Ruiz at programs@adirafoundation.org

