Introducing The PQOLI-DI: Addressing the Gaps in Quality of Life Measures for Disabled Populations

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Abstract

Objective: Quality of life (QOL) is used to assess patient happiness and life satisfaction in healthcare as a means to inform patient care. However, existing measures often fail to reflect disabled individuals' experiences. Prior studies evaluating existing measures in a disabled population suggest adding items on acceptance of disability, hope, sense of control, self-care, social participation, and trust in the healthcare (Avolio et al., 2013; Chen & Crewe, 2009; Crocker et al., 2021; Heijdra Suasnabar et al., 2024; Yoon et al., 2024). A proposed patient-centered revision adds a qualitative element to allow for individualized, goal-based care (Darabos et al., 2023; Holmes-Truscott et al., 2024; Seves et al., 2020). This study aims to develop and test a new QOL scale tailored to the needs of disabled individuals, incorporating insights from previous research and participant feedback.

Methods: Forty-four adults with disabilities were recruited via national disability organizations and the Fordham University Office of Disability Services. The revised QOL scale includes 14 Likert items with optional free responses encompassing five subscales: health, social and personal well-being, health optimism, access to resources, and attitudes towards healthcare.

Results: Thematic analysis of free responses informed scale refinement. In addition to responses to the scale questions, participants also rated their experience with the scale. Future research will assess reliability and validity.

Conclusions: This study highlights the need for QOL measures that better reflect disabled individuals' experiences, which, in turn, can facilitate better communication between patients and healthcare providers.

Study Overview

Pre-Study	During Study	Data Analysis	Future Directions
Literature Review & Scale Development	**Qualitative Responses**	**Thematic Analysis**	**Creation of the PQOLI-DI**
Current literature assessing QOL scale effectiveness in disabled sub-populations was assessed and findings were used to create the preliminary scale.	Study design was developed and approved. Participants would respond to the preliminary scale as well as questions asking about the participant's experience filling out the scale.	All 14 optional free-response items underwent thematic analysis to identify the kinds of information participants expanded upon, illustrating the potential value of these qualitative components for informing provider understanding.	Based on feedback from the thematic analyses, the scale was revised and renamed the *Personal Quality of Life Index – Disabled Individuals.* The next phase of development involves psychometric testing to evaluate its validity and reliability.

Scale Revision

Preliminary Scale:
- 14 Likert scale questions with optional free-response boxes.
- Five subscales: Health, Social and Personal Well-Being, Health Optimism, Access to Resources, Attitudes Towards Healthcare.

PQOLI-DI – Personal Quality of Life Index - Disabled Individuals:
- 16 Likert-scale and multiple-choice questions with optional free-response boxes.
- Questions about living situation and employment were added to the Social and Personal Well-Being subscale.
- Visual prompts are included for accessibility.

Methods

Adults with disabilities were recruited via email through national disability organizations and Fordham University's Office of Disability Services to complete a Qualtrics survey. Participants received a $5 gift card as compensation. The survey included demographic questions, the preliminary version of the quality of life scale, and an item assessing the perceived effectiveness of the scale. Each question featured an optional free-response section to allow for elaboration.

Table 1

Participant Sex (N=44)

Sex Assigned at Birth	Frequency (n)	Percent (%)
Female	34	77.3
Male	10	22.7
Intersex	0	0

Note. Participants self-reported sex.

Table 2

Participant Gender Identity (N=44)

Gender Identity	Frequency (n)	Percent (%)
Woman	31	70.5
Man	10	22.7
Non-Binary	2	4.3
Other	1	2.3

Note. Gender identity was self-reported.

Table 3

Participant Race (N=44)

Race/Ethnicity	Frequency (n)	Percent (%)
White	30	68.2
Multiracial	6	13.6
Hispanic or Latino	4	9.1
Black or African American	3	6.8
Asian	1	2.27
American Indigenous	0	0
Native Hawaiian or Pacific Islander	0	0

Note. Percentages may not total to 100% due to rounding.

Table 4

Disability Type Frequencies (N=44)

Disability Type	Frequency (n)	Percent (%)
Physical	33	75.0
Neurodiversity	30	68.2
Invisible	22	50.0
Emotional and Psychiatric	24	54.5
Sensory	7	15.9

Note. Participants could select multiple disability types therefore, percentages reflect the proportion of total sample (N=44).

Results - Preliminary Scale

Health Subscale: includes questions about health, both physical and mental. Questions 1-6.

Question one: Is your health right now indicative of your baseline?

(1) describing daily fluctuations in symptoms	(2) discussing situational factors impacting their health	(3) discussing recent changes (non-specific time frame)	(4) medical information regarding their health.

Question two: How is your overall physical health (bodily) right now?

(1) adherence to healthy habits	(2) sharing health accomplishments	(3) chronic and acute health symptoms	(4) struggling due to health symptoms

Question three: Has your physical health been an obstacle to carrying out your regular activities (given your expectations of your normal abilities)?

(1) lost ability	(2) difficulty with access to daily living

Question four: How is your overall mental health right now?

(1) management, such as medication influences symptoms	(2) physical symptoms negatively affect mental health	(3) situational effects on mental health

Question five: Has your mental health been an obstacle to carrying out your regular activities (given your expectation of your normal abilities)?

(1) high symptoms impact the ability to care for oneself	(2) fluctuation in symptoms makes daily and desired activities difficult or inaccessible

Question six: How much do your mental and physical health interact? For example, if your mental health is poor, it negatively affects your physical health and vice versa.

(1) symptoms overlap	(2) the interaction between them impacts the ability to care for oneself.

Social and Personal Well-Being: includes three questions evaluating different elements of well-being acceptance of disability, social participation, and self-care. Questions 7-9.

Question seven: How would you rate your acceptance of your disability?

(1) acceptance is/was challenging due to the imperceptible nature of their disability	(2) varying levels of ignoring the presence of disability and pushing without supports	(3) understanding towards disability as a part of one's life	(4) ambivalence – balancing wishing for abilities that they have lost and also recognizing it is not going to change

Question eight: How would you rate your level of satisfaction with your social life? Can you connect with others in the ways you want to, for example, in your community, your work, your church, etc.?

(1) It is challenging to maintain a social life due to symptoms	(2) aspiring to find community	(3) describing how their current social life looks

Question nine: Are you participating in self-care activities regularly? Examples: reading, crafting, hobbies, bathing, etc.

(1) listing the many self-care activities folks participate in	(2) listing why it is difficult to engage in self-care activities	(3) sharing that engaging in self-care activities are not a priority for them

Health Optimism: includes two questions, one asking participants about their sense of control over their health and another regarding their hope for change to their health within the limits of their ability. Question 10.

Question 10: How would you rate your hope for your health to improve (within your personal limits)?

(1) struggle with feeling in control due to the healthcare system	(2) feeling that their health controls them	(3) having feelings of agency

Question 11: How would you rate your feeling of control over your health?

(1) not hopeful due to specific diagnosis	(2) discussing how they are working to improve their hope (agency)	(3) sharing that their hopes are temporarily garnered due to situational factors

Access to Resources: includes a question asking about access to resources. Question 12.

Question 12: How would you rate your access to resources to support your health? I.e., Do you feel you have the necessary resources, such as doctors, financial support (SSDI) mobility aids, etc, to be as healthy as possible?

(1) they have access to resources due to financial support	2) they are in limbo waiting for resources	(3) they are missing support

Attitudes Towards Healthcare: Healthcare providers need to know a patient's past experiences and attitudes towards healthcare because it may influence their adherence to a treatment plan or interest in seeing further professionals.

Question 13: How would you rate your trust in the healthcare system?

(1) the healthcare system is a money-maker	(2) feelings are dependent on individual provider experiences	(3) struggle with trust due to feeling they have been pushed around and ignored	(4) have a positive personal experience with the healthcare system but think it is overall a mess.

Question 14: What is the most crucial aspect of your health/life that your healthcare team should know?

(1) emotional reactions to being disabled	(2) sharing what they are looking for in a provider	(3) patients have expertise that needs to be listened to, including their resilient attitudes. A compelling quote from a participant is, *"I know my body. I live here. I have a good sense of how my pain levels work, and when I speak up, I would like to be listened to".*

Acceptability: The final question of the survey asked participants about their experience filling out the scale, which fell into three broad categories:

(1) positive experience with the scale and how it captured accuracy	(2) neutrality towards the scale and its accuracy	(3) suggestions for improvement.

Key findings

In line with previous research, **many participants used free-response boxes to elaborate on their responses** (Holmes-Truscott et al., 2024). The free responses were analyzed to demonstrate the types of information that providers can gain from this scale feature.

- In the health subscale, **participants emphasized the impact of symptom fluctuations and situational factors on their health ratings;** this is aligned with the previous research (Tak, 2023). **A prominent theme was the interaction between mental and physical health,** which underscores the need for understanding how a patient's mind and body interact and impact quality of life.
- The social and personal well-being subscale highlighted previous research findings that **disabled individuals face difficulties in maintaining social connections** (Yoon et al., 2024). Additionally, themes from this subscale demonstrate how that difficulty extends to self-care, which many participants expressed boundaries to engaging in.
- The health optimism subscale found themes endorsing varying levels of feelings of control over health and hope for reasonable improvement. **Participants mentioned that a factor impacting their sense of control was their experience with providers,** which aligns with the suggestion of Darabos et al. (2023) that healthcare providers need to empower patients and foster a sense of agency within them.

Conclusions

This study begins the process of developing a comprehensive QOL measure for disabled individuals, addressing the lack of accuracy in stakeholder priorities and individualization of current measures. The unique formatting of this scale, including frequent opportunities for qualitative responses, aims to scaffold goal-focused conversations in healthcare settings. **These findings underscore the importance of creating a responsive and holistic QOL measure that includes insights from disabled individuals, ultimately leading to better healthcare outcomes and improved QOL.**

Limitations

This exploratory study may have limited generalizability due to its small, predominantly female sample and lack of age data, which could inform QOL differences across the lifespan. Participants likely have lower support needs, as they could access the survey and comprehend its content, which likely excluded from those with higher-support needs from participation. Future research should diversify samples by race, age, and gender and include testing in medical settings where data can be collected on both patient and provider experiences. The scale should also be tested in specific disability sub-groups, examining potential modifications as necessary.

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