Assessment of Patients' Quality of Life in Long COVID: A Review of Relevant Concepts and Patient-Reported Outcomes

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Background

- Since the onset of the Coronavirus Disease 2019 (COVID-19) pandemic there have been challenges in diagnosing long COVID (also known as post-acute COVID syndrome or post-COVID conditions), leading to potential underdiagnosis and missed opportunities for treatment.
- Using Patient-Reported Outcome (PRO) are key to better consider the patients' voice and impact of the disease on their quality of life, and to support the development of treatments that are patient-centered and address patients' concerns with disease impacts on their quality of life.

Objectives

A. To understand how long COVID impacts quality of life (patient-reported measurement concepts)
B. To identify concepts that were measured, and PROs used in clinical trials on long COVID
C. To identify PROs specifically developed and validated in long COVID

Methods

A. Identifying concepts relevant to long COVID patients

- <u>Medline and PsycInfo</u>: Primary search was performed for **qualitative studies** in long COVID patients (published before January 2023): 353 articles reviewed → 14 studies selected for data extraction
- <u>Grey literature</u>: Supplementary search in selected online patient blogs/stories was performed to identify qualitative reports mentioning other relevant concepts important to the patients (1. *World Health Organization [1]*; 2. *British Heart Foundation [2]*; 3. *Long COVID Ireland [3]*; 4. *Long COVID SOS [4]*; 5. *Hounslow and Richmond Community Healthcare NHS Trust [5]*; 6. *Alberta Health Services [6]*): 6 reports selected for data extraction

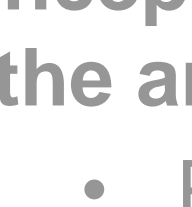**B. PROs and measurement concepts assessed in long COVID clinical studies**

- <u>Medline</u>: Search performed to identify PRO instruments used and concepts assessed in long COVID clinical studies before August 2022: 650 studies reviewed → 133 selected for data extraction
- <u>ClinicalTrials.gov</u>: Search performed to identify PRO instruments used and concepts assessed in long COVID interventional studies before March 2023: 214 studies reviewed → 147 selected for data extraction

C. PROs specifically developed for long COVID patients

- Search performed in PROQOLID™ database[7] in May 2023 to identify PROs developed for patients for long COVID patients and identify the concepts of interest assessed in these studies: 8 PROs identified

Findings

A. Concepts impacting patient Quality of Life

- Illness journey/experience
  Physical functioning, disability
- Emotional and Cognitive Functioning
  Activities of daily living
  Coping
- Social functioning
  Family functioning
- Work/school impact (including financial)

B. Concepts measured in the clinical trials

Concepts that were measured across majority (>50%) of the analyzed endpoints:
- Physical functioning, disability (functional status)
- Fatigue
- Mental health, emotional functioning
- Cognitive functioning
- Dyspnea

Concepts that were assessed in less than 5% of the total endpoints:
- Social and family functioning
- Coping
- Activities of daily living
- Illness journey

C. PROs developed for long COVID population (source: PROQOLID)

Full PRO name	Concepts
Post-COVID-19 Functional Status scale (can also be used as Clinician-Reported Outcome)	Symptoms, Functional limitations
Symptom Burden Questionnaire™ for Long Covid	Symptoms
COVID-19 Yorkshire Rehabilitation Scale	Symptoms, Functional limitations, Overall health
Modified COVID-19 Yorkshire Rehabilitation Scale	Symptoms, Functional limitations
Long COVID Symptom Tool	Symptoms
Long COVID Impact Tool	Disease impact
Functional Compass COVID-19	Symptoms
Post-Acute (long) COVID-19 Quality of Life Questionnaire	Quality of life

B. Top PROs used in long COVID clinical studies by development population

Developed for **Long COVID** * (Frequency in Medline|CT.gov)	Generic (Frequency in Medline|CT.gov)	Other disease-specific (Frequency in Medline|CT.gov)
Post-COVID-19 Functional Status scale (14|22)	SF-36 Health Survey (12|41)	Hospital Anxiety and Depression Scale (25|19)
Symptom Burden Questionnaire™ for Long Covid (3|6)	EuroQoL 5-Dimension (4|22)	Modified Medical Research Council Dyspnea Scale (20|20)
COVID-19 Yorkshire Rehabilitation Scale (3|2)	Borg Dyspnea Scale (4|9)	Fatigue Severity Scale (12|24)
Long COVID Symptom Tool (3|0)	SF-12 Health Survey (5|8)	Generalized Anxiety Disorder – 7 (10|16)
Long COVID Impact Tool (3|0)	Patient-Reported Outcomes Measurement Information System - 29 Profile v2.1 (3|5)	Patient Health Questionnaire - 9-item (12|13)

* Only 4% of all PROs used in long COVID studies were specifically developed for long COVID patients

Key insights & Discussion

A. Physical, psychological, social and cognitive functions are among the most important impact of the disease mentioned by the patients. While these symptoms are key to better understand natural history of the disease and develop better diagnostic criteria, it is important to develop treatments that best address these aspects Lof quality of life.

B. There are few trials that focus on social and family functioning, coping and activities of daily living as key endpoints. More research on this area is needed to improve overall quality of life of the patients.

C. By the time of this study only 4% of all clinical trials used instruments that were specifically developed for long COVID patients. The rapid response against COVID led to extensive clinical research while the understanding of the disease (acute form or long-COVID) was still in early phases

References: 1. https://www.who.int/europe/home?v=welcome; 2. https://www.bhf.org.uk/informationsupport/heart-matters-magazine/my-story; 3. https://www.longcovidireland.org/; 4. https://www.longcovidsos.org/stories; 5. https://www.youtube.com/watch?v=d6yXya8I2-k; 6. https://www.youtube.com/watch?v=tB6xxp5GK7Y