A Systematic Review & Metaethnography of the lived experiences of long COVID patients

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Method Article

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Abstract

Background:

‘Long Covid’ is the term used to signify signs and symptoms that emerge or develop after acute COVID-19. It constitutes both ongoing symptomatic COVID-19 and post-COVID-19 symptoms. Symptoms of “long COVID” include fatigue, muscle weakness, sleep difficulties, anxiety and depression, amongst other physiological signs of illness. While previous studies have highlighted the symptoms and epidemiological characteristics of ‘long COVID’, the implications of ‘long COVID’ extend well into the mental well-being of the patients, affecting their everyday lives. The present systematic review and meta-ethnography attempt to reveal deeper insights from the lived experiences of long COVID patients, which has clinical implications for improving future care and formulating clinical guidelines for future use.

Methods and analysis:

We performed a systematic review and meta-ethnography on the lived experiences of “long COVID” patients using Reciprocal Translation Analysis (RTA), Refutation Analysis, and Line-of-Argument synthesis. Electronic databases of EMBASE (Ovid), AMED (Ovid), HMIC (Ovid), BNI (ProQuest), CINAHL(EBSCO), EMCORE(Ovid), PsycINFO(ProQuest), Medline/PubMed, Web of Science (Clarivate Analytics) and Google Scholar were searched using a combination free texts and MeSH terms. A combination of the terms “long COVID” AND “survivors” AND “lived experiences” with their corresponding synonyms were used as a search strategy. Further, we limited search results to peer-reviewed primary studies published in the English language from 2019 till May 18th, 2021. Citation tracking, footnote chasing, bibliography scanning, and citation alerts (on the web of science) were further performed to create a comprehensive search. The retrieved search results were managed on the COVIDENCE platform, where eligible studies were identified after screening the articles based upon preidentified eligibility criteria. The quality of the eligible studies was further assessed through critical appraisal using the CASP Tool for Qualitative Studies.

Findings: 1120 articles were retrieved from the search strategy, of which 774 unique articles were subjected to title & abstract screening after removing the duplicates. Furthermore, a full-text review of eligible studies after title & abstract screening was performed to ultimately include 6 studies that matched the eligibility criteria for this review. Based on the analysis of the critical appraisal, no studies were rejected. The majority of the studies were from the UK, with the study population skewed towards white British ethnicity and mostly female participants. The meta-ethnography attuned to a lifeworld perspective revealed four key themes: struggle & strife over self-identity; searching for a shared identity & belongingness; uncertainty & mistrust of the care system; seeking reassurance from others. The long covid patients were in a state of confusion with their illness symptoms and sought reassurance from the caring professionals when confronted with a loss of self-identity due to illness. Helplessness, frustration, anxiety, and depression affected the participants, resulting in the depreciation of their self-esteem. Uncertainty overdiagnosis of the illness symptoms along with limited face-to-face interaction with caring professionals led the participants to a state of helplessness and a resilient search for online support.
groups with similar symptoms. In a nutshell, this study revealed a state of constant struggle and strife over the self-identity of participants, along with an urge to belong back to the lifeworld.

**Conclusions:** The present study offers key insights into the lives of long-covid patients and can be especially helpful in formulating future clinical guidelines for long-covid patients. The uncertainty over symptoms and diagnosis of long COVID is affecting the general population and healthcare professionals alike. Understanding the lifeworld of long-COVID patients could allow clinicians to create customized self-care plans for them and provide an opportunity for improvement in their psychosocial health in these uncertain times.

**Procedure**

We performed a Systematic Review and Meta-ethnography on the lived experiences of “long COVID” patients using Reciprocal Translation Analysis (RTA), Refutation Analysis and Line-of-Argument synthesis. Electronic databases of EMBASE(Ovid), AMED(Ovid), HMIC(Ovid), BNI(ProQuest), CINAHL(EBSCO), EMCARE(Ovid), PsycINFO(ProQuest), Medline/PubMed, Web of Science (Clarivate Analytics) and Google Scholar were searched using a combination free texts and MeSH terms. A combination of terms “long COVID” AND “survivors” AND “lived experiences” with their corresponding synonyms were used as a search strategy. Further, we limited search results to peer reviewed primary studies published in English language from 2019 till 18th May 2021. Citation tracking, footnote chasing, bibliography scan and citation alerts (on the web of science) were further performed to create a comprehensive search. The retrieved search results were managed on the COVIDENCE platform where eligible studies were identified after screening the articles based upon preidentified eligibility criteria. The quality of the eligible studies were further assessed through critical appraisal using the CASP Tool for Qualitative Studies.