Research Square

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Investigating care outcomes and experiences of adults with Long COVID through patient- reported indicators (PROMs and PREMs) in Belgium

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Abstract

Background:

Long COVID, with its multisystemic manifestations, poses a substantial burden on health systems. Nevertheless, evidence regarding Long COVID patients' perspectives, perceived health outcomes and care experiences in Belgium remains limited.

Methods:

OECD's Patient-Reported Indicator Surveys (PaRIS) collected patient-reported outcome and experience measures (PROMS and PREMs) from individuals aged 45+ with chronic conditions. In Belgium, 4,687 primary care patients provided self-reported data between March 2023 and January 2024.

This study explores the associated clinical and sociodemographic factors, care outcomes and experiences of adults with Long COVID in Belgium, by comparing respondents with and without Long COVID. Multivariate models were used to examine the clinical and sociodemographic determinants of Long COVID, and mixed-effects models were applied to compute the 10 key PROM and PREM indicators following the PaRIS10 methodology, accounting for the hierarchical structure of the data (patients nested within GP practices).

Results:

Overall, 50% (N=2,359) had a previous COVID-19 infection diagnosis, and over one in four (26%) of them reported Long COVID-related symptoms lasting 2 months or longer after COVID-19 infection (N=605, 12.9% overall prevalence).

Higher risk of Long COVID was associated with being female, aged 45-54, lower educated, having multiple chronic conditions and higher BMI.

Long COVID adults reported significant lower PROM scores for general health, wellbeing, physical and mental health compared to non-Long COVID respondents. Those with Long COVID symptoms lasting at least 1 year reported even poorer outcomes, particularly in general health, wellbeing and physical health.

PREMs showed no significant differences between Long COVID and non-Long COVID respondents overall. However, trust in healthcare system and person-centred care was significant lower when Long COVID patients still had these long-term symptoms at survey time.

Conclusions:

In Belgium, adults with Long COVID report poorer health outcomes and less positive care experiences compared with those without Long COVID. These findings point to the substantial burden associated with Long COVID and to gaps in the current healthcare response to this emerging condition. Strengthening dedicated care pathways, improving coordination across services, and ensuring clear communication and support for patients will be essential to better address the needs of people living with Long COVID.

Background

Long COVID (also known as post-acute sequelae of COVID-19) is a multi-systemic condition comprising persistent symptoms (> 4 weeks) following the acute SARS-CoV-2 infection [1]. Long COVID is characterized by a wide range of symptoms that vary in nature and intensity, commonly including chronic fatigue, cognitive impairment ("brain fog"), respiratory difficulties, musculoskeletal pain, and cardiovascular issues [2–3]. Individuals living with Long COVID experience a significant reduction in quality of life, affecting physical, mental and social health, causing disability and reduced productivity [2;4–5]. Moreover, recovery from Long COVID remains uncertain for millions of patients worldwide [1;5].

Worldwide, people living with Long COVID have large healthcare needs, leading to increased healthcare utilization, additional healthcare and disability spending [2;4]. The impact of Long COVID extends beyond individual patients and challenges the capacity of healthcare systems. Services for Long COVID vary widely within and between healthcare systems. Furthermore, over the past years, Long COVID has raised growing concerns among healthcare professionals [1;6]. Primary care is at the forefront in caring for Long COVID patients and general practitioners (GPs) take up a key position as they are typically the first point of contact for patients experiencing persistent Long COVID symptoms [7]. As Long COVID symptoms may persistent for months, multidisciplinary approach to diagnosis and treatment is required [5–6]. A few countries, such as Belgium, France and Germany, have reported a national care trajectory for Long COVID with various level of implementation [8]. Unfortunately, due to the variability in Long COVID services, most people with Long COVID describe them as insufficient, and barriers to healthcare access, diversity in quality and equity of care have been identified [6;9–10].

In this regard, capturing Long COVID patients' perspectives on perceived health outcomes and care experiences using patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) in primary care is an important approach [11]. Patient-reported indicators (PROMS, PREMS) are important for monitoring the quality of care and developing policies and practices in countries. Integrating patients' perspectives in the approach to Long COVID enriches the understanding of care experiences and inform patient-centred care models. As

information on Long COVID patients' perceived health outcomes and care experiences is scarce for Belgium, this article aims to contribute to this knowledge gap.

This study aims to investigate care outcomes and experiences of adults living with Long COVID in the general Belgian population, this through patient-reported indicators (PROMs and PREMs).

Methods

Study population and design

OECD's Patient-Reported Indicator Surveys (PaRIS) is a cross-sectional survey capturing patient-centred outcomes and experiences for individuals aged 45 years and older living with chronic conditions [12]. The PaRIS patient questionnaire (PaRIS-PQ) used in this study has been published and is publicly available on OECD's website [13]. As part of this initiative, self-reported data was obtained from primary care patients from March 2023 to January 2024 in Belgium. A total of 4,687 patient survey responses (59.7% completed online, 40.3% on paper) were collected, which resulted in a 33.4% participation rate for Belgium. Information about GP and patient recruitment, participation and representativeness are available in the national report [14].

The core analysis of this study includes 2,359 participants (50.3%) who answered 'yes' to the question: 'Have you ever tested positive for COVID-19 (using a rapid point-of-care test, self-test, or laboratory test) or been told by a doctor or other health care provider that you have or had COVID-19?'. When answering 'yes' on the former question, respondents received additional questions related to Long COVID. These COVID-related questions were based on those of the US Pulse household survey [15]. On the question 'Did you have any symptoms lasting 2 months or longer that you did not have prior to having coronavirus or COVID-19?' *(Long term symptoms may include: tiredness or fatigue, difficulty thinking, concentrating, forgetfulness, or memory problems (sometimes referred to as "brain fog", difficulty breathing or shortness of breath, joint or muscle pain, fast-beating or pounding heart (also known as heart palpitations), chest pain, dizziness on standing, menstrual changes, changes to taste/smell, or inability to exercise')*, respondents could indicate the persistence of symptoms by choosing (1) Yes, symptoms lasted between 2–3 months, (2) Yes, symptoms lasted between 3–6 months, (3) Yes, symptoms lasted between 6 months – 1 year, (4) Yes, symptoms lasted at least 1 year, (5) No and (6) Not sure. When answering (1) to (4) on the Long COVID question, participants could indicate if they still have symptoms at survey time ('Do you still have these long-term symptoms?') by answering (1) Yes, (2) No and (3) Not sure.

Measures

This study investigates differences in care outcomes and healthcare experiences between adults living with and without Long COVID in Belgium. The primary dichotomous outcome variable was the Long COVID status, i.e. whether or not people self-reported Long COVID-related symptoms lasting 2 months or longer after COVID-19 infection.

In addition, the following collected sociodemographic characteristics and risk factors were included as covariates in the analysis: age, gender, educational level, Body Mass Index (BMI) and number of chronic conditions.

To assess Belgium's healthcare performance through a patient-centred lens, the ten key indicators from the PaRIS10 Dashboard were used [12]. The PaRIS10 Dashboard includes five PROMs that capture essential aspects of health: physical health, mental health, social functioning, well-being and general health. In addition, five PREMs offer insight into critical interactions with healthcare services: confidence to self-manage, experienced care coordination, person-centred care, experienced quality of care and trust in health system. The national report provides detailed information on the construction of these ten key indicators [14].

Data management and informed consent

Data were collected through both an online survey platform provided by Ipsos and paper questionnaires distributed by a third-party provider (TTP). Participants were encouraged, via the invitation letter, to complete the online survey. Those who preferred a paper version could request one by mail or by phone, or use the paper questionnaire included in the second reminder mailing. Informed consent was obtained from all participants included in the study. All methods were carried out in accordance with the declaration of Helsinki.

Statistical analysis

Descriptive statistics were conducted to summarize respondents' characteristics and key outcome variables. Chi-square test ($p < 0.05$) was used to determine if there was a significant association between the categorical variables 'Long COVID symptom persistence' and 'Long COVID-related symptoms at survey time'. Missing data for the primary outcome were minimal (N = 20, 0.8%) and missingness in covariates was low (< 11%).

To optimize the representativeness of the results, the standardization variables (age and gender) in the models were rescaled to align with the 2023 Belgian population (aged 45+), using data retrieved from the Belgian national statistical office (STATBEL) [16].

Association between participant's sociodemographic characteristics and risk factors, and the Long COVID status was assessed through a multivariate logistic regression model. Odds ratios (OR) and 95% confidence intervals (95% CI) were reported. A p-value < 0.05 was considered statistically significant.

Multilevel models were conducted, taking into account the hierarchical structure of the data (GP practices – patients). Depending on the nature of the dependent variable, linear (continuous outcomes) or logistic (dichotomous outcomes) mixed-effects models were constructed, adjusted for age, gender and number of chronic conditions. These mixed-effects models were applied to compute the PaRIS10 indicators, in which values differing significantly ($p < 0.05$) from the reference group (participants without Long COVID) were indicated.

Data management and analysis were performed in R version 4.4.1 and above.

Results

The sociodemographic and clinical characteristics of the respondents (adults aged 45+) are presented in Table 1. Among the study participants, 51.6% were women, 56.0% were between 45–64 years old and 41.9% had a higher education. Of all respondents, 52.6% were overweight or obese, and one in five had no chronic condition.

Table 1
Sociodemographic and clinical characteristics of study participants (N = 4,687)

	N	%
Socio-demographic characteristics		
Age categories		
45–54 years old	1110	23.7
55–64 years old	1515	32.3
65–74 years old	1379	29.4
75 + years old	661	14.1
Missing	22	0.5
Gender		
Female	2420	51.6
Male	1940	41.4
Other	11	0.2
Prefer not to say	26	0.6
Missing	290	6.2
Level of education		
No education, primary or lower secondary education	1227	26.2
Higher secondary education	1305	27.8
Higher education	1965	41.9
Missing	190	4.1
Risk factors		
Body mass index (BMI) - WHO classification		
Underweight (< 18.5)	70	1.5
Normal (18.5–24.9)	1645	35.1
Overweight (25–29.9)	1654	35.3
Obesity (≥ 30.0)	813	17.3
Missing	505	10.8
BMI continuous (mean + SD)	*26*	*4.6*
Chronic disease		
Yes	3503	74.7
No	958	20.4
Missing	226	4.8
Clinical characteristics		
Previous COVID-19 diagnosis		
Yes	2359	50.3
No	2097	44.7
Not sure	50	1.1
Missing	181	3.9
If yes on previous COVID-19 diagnosis: Long COVID-related symptoms (n = 2,359)		
Yes, symptoms lasted between 2–3 months	320	13.6

	N	%
Socio-demographic characteristics		
Yes, symptoms lasted between 3–6 months	99	4.2
Yes, symptoms lasted between 6 months – 1 year	68	2.9
Yes, symptoms lasted at least 1 year	118	5.0
No	1588	67.3
Not sure	146	6.2
Missing	20	0.8
If yes on Long COVID-related symptoms: symptoms at survey time? (n = 605)		
Yes	165	27.3
No	352	58.2
Not sure	77	12.7
Missing	11	1.8

Half (50,3%; N = 2,359) of respondents reported having tested positive for or being diagnosed with COVID-19. Among those who had experienced COVID-19, over one in four (25.6%, N = 605) reported Long COVID-related symptoms beyond 2 months and 5.0% (N = 118) reported persistent symptoms beyond 12 months. Among participants who had experienced Long COVID-related symptoms (N = 605), about one in four (27.3%, N = 165) reported still experiencing symptoms at the time of the survey, with 58.8% of these reporting symptoms that had lasted at least 1 year ($p < 0.001$).

For Belgium, an overall Long COVID prevalence of 12.9% among primary care 45 + adults is estimated. When applying the stricter WHO case definition (i.e. persistence of symptoms > = 3 months after initial COVID-19 infection) [17], Long COVID overall prevalence in primary care is 6.1% for Belgium.

The logistic regression results show several important associations with Long COVID (Fig. 1). Being male was associated with a 37% lower odds of having Long COVID compared to females (OR = 0.63, $p < .001$). Age was also a significant factor, with older age groups showing progressively lower odds of Long COVID: 26% lower odds for 55–64 years old adults (OR = 0.74, $p < .05$), 42% lower odds for adults aged 65–74 years (OR = 0.58, $p < .001$), and 62% lower odds for 75+'ers (OR = 0.38, $p < .001$), compared to the youngest age group 45–54 years old. On the other hand, having more chronic conditions increased the risk: each additional chronic condition was associated with a 28% higher odds of Long COVID (OR = 1.28, $p < .001$). Compared to respondents with lower education, those with higher education having a 54% lower odds of Long COVID (OR = 0.46, $p < .001$). BMI was also linked to Long COVID, where each unit increase in BMI was associated with a 3% higher odds of Long COVID (OR = 1.03, $p < .05$).

Table 2 presents the results for PaRIS10 indicators by Long COVID status and patient-reported persistence of symptoms. Adults with Long COVID reported significantly lower PROM scores for general health, wellbeing, physical and mental health compared to respondents without Long COVID. When symptom duration was taken into account, a strong physical health impact among all individuals with Long COVID was observed. Respondents mentioning short-term Long COVID symptoms (2–3 months) indicated a clear impact on general health, wellbeing, physical and mental health. Wellbeing was significant lower for those with symptoms lasting 6 months to 1 year, and individuals with symptoms persisting at least 1 year reported even poorer outcomes, particularly in general health, wellbeing and physical health. Moreover, when having these persistent symptoms at survey time, Long COVID adults self-rated all care outcomes significant lower, except for social functioning.

Table 2
PaRIS10 indicators by Long COVID status (N = 2,193)

	Patient-reported outcome measures (PROMs)					Patient-reported experience measures (PREMs)				
Long COVID (LC)	**General health (%)**	**Well-being (/100)**	**Physical health (16.2–67.7)**	**Mental health (21.2–67.6)**	**Social functioning (%)**	**Experienced quality of care (%)**	**Confidence to self-manage (%)**	**Trust in healthcare system (%)**	**Experienced coordination (/15)**	**Person-centred care (/24)**
Positive Outcomes	Good, very good, excellent	≥ 50	≥ 42	≥ 40	Good, very good, excellent	Good, very good, excellent	Confident, very confident	Agree, strongly agree	≥ 7.5	≥ 12.0
No Long COVID (n = 1,588)	81.7	64.5	48.3	47.9	90.6	96.8	69.5	73.7	9.27	18.3
Long COVID (n = 605)	71.3*	56.5***	43.9***	45.7***	86.1	96.1	64	64.6	8.69	17.4
LC, symptoms lasted between 2–3 months (n = 320)	71.2*	56.8***	43.9***	45.2***	85.5	95.4	63.5	64.2	8.76	17.7
LC, symptoms lasted between 3–6 months (n = 99)	80.1	58.4	45.7*	46.6	86.5	98.2	63.8	72.2	8.65	16.9
LC, symptoms lasted between 6 months – 1 year (n = 68)	68.6	57.2*	43.5***	45.7	89.7	94.2	56.1	65	8.51	16.7
LC, symptoms lasted at least 1 year (n = 118)	65.7*	53.6***	42.8***	46.4	85.1	97.1	69.9	58.8	8.59	17.2
LC, long-term symptoms at survey time (n = 165)	60.2**	50.2***	40.7***	45.4***	82.4	95.3	63	57.2***	8.29	16.5***

Asterisks denote levels of statistical significance (* p < .05, ** p < .01, *** p < .001) relative to the reference category (No Long COVID).

Results are adjusted for age, gender & number of chronic conditions, taking into account the hierarchical structure of the data. Data is weighted using STATBEL 2023 > = 45 years old.

Self-reported experience measures (PREMs) showed no significant differences between Long COVID and non-Long COVID respondents overall (Table 2). However, trust in healthcare system and person-centred care was significant lower when adults with Long COVID still had these long-term symptoms at survey time.

Discussion

Key findings

In this study, the primary care-based survey of PaRIS was used to provide estimates of the impact of Long COVID in the general population using primary care services. In Belgium, among primary care adults aged 45 years and older who have been infected with COVID-19, more than one in four (25.6%) reported persistent Long COVID-related symptoms beyond two months and for 5.0%, symptoms persisted beyond a year. Among 45 + Belgian adults, an overall Long Covid prevalence of 12.9% is estimated when symptoms persisted beyond two months, and 6.1% when persistence

of symptoms is > = 3 months after the initial COVID-19 infection. These results are in line with other Belgian population sources. A survey among the general Belgian population (not focusing on individuals in contact with healthcare) estimated the prevalence of Long COVID among people aged 15 years and older on 4.2% when symptoms persisted at least 3 months [18]. Based on data from 16 OECD countries collected through the PaRIS survey, Long COVID prevalence (persistent symptoms > = 3 months) is estimated at 7.2% of the primary care population aged 45 years and older, with Belgium presenting comparable estimates to our surrounding countries (France, Netherlands, Germany, etc.) [8].

This study shows that adults with living Long COVID were more likely to be female, aged 45–54 years old and with a lower education level, echoing prior studies [19–20]. Higher risk of Long COVID was also associated with having multiple chronic conditions and a higher BMI, confirming other studies [21–22].

Through patient-reported indicators, care outcomes and experiences of adults with Long COVID in Belgium could be investigated. In this study, substantial differences in self-reported care outcomes were found between Long COVID and non-Long COVID respondents. Adults living with Long COVID reported poorer health outcomes for general health, wellbeing, physical and mental health. These results are in line with the study of Smith et al. [23] who reported a significant decline in health-related quality of life three months after SARS-CoV-2 infection among adults with Long COVID. Brus et al. [24] found that respondents 3–6 months post-acute infection had the worst health outcomes, with the lowest health-related quality of life, the highest fatigue level and highest proportion with a likely depressive disorder. The study of Scott et al. [25] confirmed this in a longitudinal study over two years by concluding that participants with Long COVID exhibited the worst health-related quality of life and mental well-being compared to non-Long COVID groups. The physical health impact of Long COVID for adults has been confirmed in various studies [23;26–28].

By taking into account symptoms' persistence reported by people living with Long COVID, evolution in daily life burden is also explored in this study. These results on persistence of symptoms revealed that people perceived a strong overall health impact during the onset of Long COVID symptoms (first 2–3 months) and when symptoms lasted a year or longer. The study by Tran et al. [29] observed a U-shaped trend in the development of the perception of Long COVID impact on patient's lives. Tran et al. found an aggravation six months after onset and theorized that this exacerbation relates to patients' realization that persisting symptoms might be chronic rather than temporary. This is in line with the evolution in worsening of health outcomes found in this study where poorer outcomes in general health, wellbeing and physical health were reported when symptoms persisted at least one year.

Adults with Long COVID symptoms at the time of the survey expressed lower trust in the healthcare system and reduced scores on person-centred care compared to non-Long COVID respondents. These results align with the study of Brus et al. [9] who encountered help-seeking barriers, issues in availability of care and financial barriers among people with Long COVID. Former studies also confirmed that people feel that Long COVID care doesn't align with their patient needs and preferences, and many patients still face neglect, stigma and inadequate support [10;30–32]. This is also the case in Belgium where patients with Long COVID report unmet needs among others in care delivery, support, access to inclusion in the Long COVID care trajectory [33–34]. Moreover, as the majority of our study respondents were at survey time confronted with severe Long COVID symptoms (i.e. persistent symptoms for at least 1 year), these adults had higher care needs and service use, encountered higher care barriers and major health and life disruptions, including absenteeism from work or school [35]. Over the past pandemic years, Long COVID patients are not the only one reporting challenges navigating healthcare. Healthcare professionals also echo the need for a clear case definition, specific clinical guidelines, diagnostic tools and interdisciplinary support for Long COVID management [2;6;36]. The need for coordinated and integrated primary and secondary care for Long COVID, also recognized among Belgian GPs [37] may explain these lower scores in our study.

Strengths and limitations

Strengths of this study are OECD's design of the PaRIS study, the use of standardised validated measures (PROMS and PREMS) and focus on ten study key indicators (the PaRIS10). This study has a population-based approach as the PaRIS survey concentrates exclusively on primary care users. Moreover, patient-reported indicators were collected on numerous adults with self-reported Long COVID (N > 600) in Belgium.

This study has several limitations. The main limitation is the selection bias due to the design of the study. Adults with chronic conditions were overrepresented in our sample which limits generalizability. Moreover, Long COVID status was self-reported and measured as patient-reported persistence of symptoms, without confirmation based on medical records or diagnosis. Adults who recovered quickly or did not self-identify as having Long COVID may be missed in this study.

Conclusion

This study provides a deeper understanding of care outcomes and experiences of adults with Long COVID in Belgium, this through the collection of PROMS and PREMS among people aged 45 + consulting primary healthcare. This study found that adults living with Long COVID report poorer health outcomes and less positive care experiences compared to those without Long COVID, especially when symptoms persisted beyond one year. These results suggest shortcomings in the current Belgian response to Long COVID, including limited structured care pathways, variability in access to coordinated and multidisciplinary services, and insufficient support for patients with persistent symptoms.

Capturing healthcare through the eyes of people suffering from Long COVID enrich our understanding of care experiences and inform patient-centred care models and health policy. Through the establishment of care pathways, interdisciplinary collaboration and coordinated management can further be expanded for Long COVID patients. Adequate training and support for healthcare professionals in primary and secondary care, and monitoring integrated care pathways for the long-term management of Long COVID can improve the experience of healthcare for adults with Long COVID in Belgium.

Declarations

Ethics approval and consent to participate

The study has been approved by the ethics committee of Erasmus Hospital Brussels (EC reference number: P2021/385/B4062021000203). Informed consent was obtained from all participants included in the study. All methods were carried out in accordance with the declaration of Helsinki.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Author contributions

SM, RE and DA designed the study. RE and DA collected the data. SM and RE performed the analysis and interpretation of the data. SM drafted the manuscript and RE, PS, NS, SB, RD and DA critically revised the manuscript. All authors approved the final version of the manuscript.

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Figures

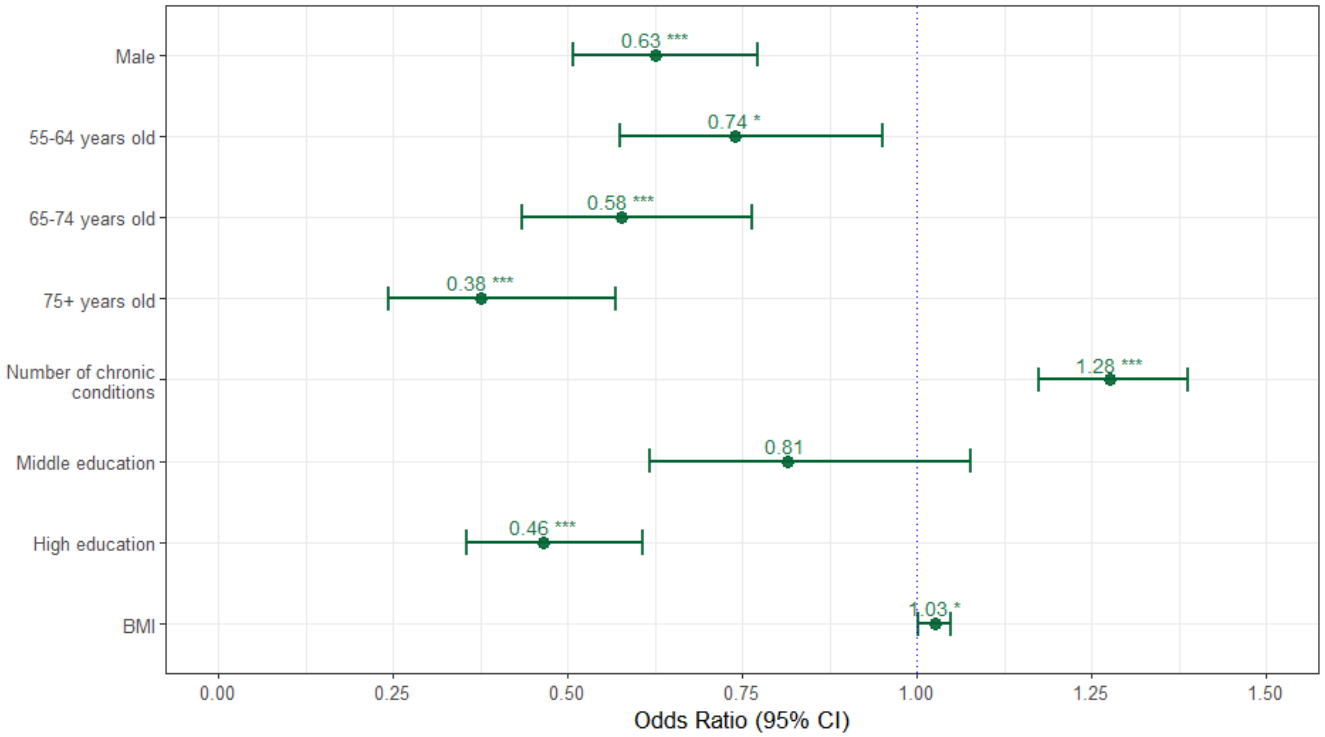

Figure 1

Associationbetween clinical and sociodemographic characteristics and Long COVID among study participants (N=2,007)