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Reshaping Long COVID Care Through Patient-Reported Needs

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Abstract

Background: Long COVID is a multisystem condition characterized by persistent or fluctuating symptoms following acute SARS-CoV-2 infection. Despite increasing scientific evidence, the alignment between patient needs and healthcare delivery remains limited. This study aimed to assess unmet clinical, psychological, and lifestyle needs among individuals previously evaluated at the Modena Long COVID Clinic and to inform a patient-centered redesign of Long COVID services.

Methods: This observational study included individuals assessed at least once at the Modena Long COVID Clinic (Italy) between August 2020 and July 2025. Participants with valid email and phone contacts were invited to complete an online questionnaire exploring unmet needs across clinical, mental health, welfare, and lifestyle domains. The questionnaire also assessed Long COVID symptom clusters and health-related quality of life (HR-QoL) using

the EQ-5D-5L and EQ-VAS. Data were compared between the first clinical visit (baseline) and the follow-up survey.

Results: Of 707 individuals contacted, 162 (22.9%) completed the survey (median age 56 years; 54.9% male). At follow-up, 80.1% reported at least one Long COVID symptom cluster, with significant increases in musculoskeletal (30.1% vs 60.8%), neurocognitive (23.5% vs 52.4%), and psychological (25.3% vs 51.2%) domains. EQ-5D-5L scores remained stable (median 83.0 vs 84.1; p=0.927), while self-rated health improved (60 vs70; p<0.001). Unmet needs were common: 22.2% reported insufficient access to specialist consultations, 15.4% lacked psychological support, and 15.5% reported unmet needs for pain management.

Conclusions: This study identifies substantial gaps between patient needs and existing care structures, emphasizing the need for a dynamic, cluster-based, and patient-centered approach. The results support the redesign of Long COVID services into five operational pillars: functional triage, empowerment and education, integrated cluster clinics, continuity of care through case management, and outcome-based evaluation. Such reorganization may enhance perceived health and well-being even when overall disability remains stable.

Trial registration: Clinical trial number not applicable.

Background

Long COVID, also termed post-acute sequelae of SARS-CoV-2 infection (PASC), is a complex, multisystemic condition affecting a substantial proportion of individuals recovering from acute COVID-19. Estimates from the recent meta-analysis suggest a global prevalence of approximately 36%, and 45% with persistence of symptoms up to two years post-infection and notable heterogeneity across populations [1–4]. The most frequently affected domains include respiratory, neurological, psychological, and fatigue-related subtypes, each contributing to a significant and sustained burden on health and daily functioning [5,6]

Despite growing evidence on prevalence and pathophysiology, there remains a striking gap between patient needs and healthcare provision. Studies have identified persistent immune activation and inflammatory biomarkers in individuals with post-acute COVID-19 sequelae, indicating a biological basis that interacts with psychological and social determinants to shape long-term

outcomes [7–9]. These findings highlight the necessity of comprehensive, patient-centered care rather than a purely biomedical approach.

Recent clinical updates underscore that individuals living with Long COVID frequently experience fluctuating symptoms such as fatigue, cognitive dysfunction, dysautonomia, pain, anxiety, and depression, often extending beyond one year after infection. These manifestations are associated with diminished quality of life, reduced work capacity, and limited participation in social and occupational roles. Long COVID management requires a model that integrates physical, psychological, and social rehabilitation, recognizing the interplay between biological and behavioral dimensions of recovery [10].

Traditional healthcare models, oriented toward episodic or organ-specific care, are insufficient to address the dynamic and multi-domain trajectory of Long COVID. Evidence from multidisciplinary cohorts and consensus frameworks supports the need for longitudinal, adaptive, and personalized care pathways [11]. However, most healthcare systems lack structured mechanisms for monitoring patient-reported outcomes, unmet needs, and evolving symptom clusters.

In this context, the present study aims to bridge this gap by systematically mapping the unmet clinical, psychosocial, and lifestyle needs of individuals previously evaluated for Long COVID at the Modena Long COVID Clinic [12]. By analyzing patient-reported experiences and longitudinal variations in symptom clusters and health-related quality of life, this research seeks to inform the redesign of Long COVID services toward a patient-centered, cluster-based model focused on living well with the condition rather than pursuing a definitive cure.

The primary objective of this study was to investigate unmet needs among individuals living with Long COVID through a structured online questionnaire addressed to people who had previously been clinically evaluated for Long COVID in an outpatient setting. Specifically, the study aimed to explore which clinical, mental health, welfare, and lifestyle services were perceived as most needed by people affected by Long COVID.

A secondary objective was to examine changes in Long COVID symptom clusters and in health-related quality of life (HR-QoL) between the initial clinical assessment (baseline) and the follow-up questionnaire.

Materials and Methods

Study Design, Inclusion and Exclusion Criteria

This was an observational study including individuals who had been evaluated at least once at the Long COVID Clinic of Modena, Italy, between August 2020 and July 2025. The Modena Long COVID Clinic is a multidisciplinary referral center established after the first wave of the COVID-19 pandemic in 2020, where patients undergo systematic screening for signs and symptoms of Long COVID.

At the clinic, Long COVID diagnosis was defined according to the WHO criteria as the persistence or recurrence of one or more symptoms at least 12 weeks after acute SARS-CoV-2 infection, encompassing neurocognitive (brain fog, dizziness, confusion), autonomic (chest pain, tachycardia, palpitations), gastrointestinal (diarrhea, abdominal pain, vomiting), respiratory (fatigue, dyspnea, cough, sore throat), musculoskeletal (myalgia, arthralgia), psychological (post-traumatic stress disorder (PTSD), anxiety, depression, insomnia), sensory (anosmia, ageusia, hypoacusis), and dermatological (hair loss, rash) clusters [12,13].

Initially, clinical evaluations were scheduled approximately twice per year per patient and subsequently adjusted based on the persistence or remission of Long COVID-related symptoms.

Inclusion criteria

All individuals with a valid email address and mobile phone number who had attended the clinic at least once were invited to participate in an online structured questionnaire investigating clinical, mental health, welfare, and lifestyle needs. The survey was administered between September 4 and September 15, 2025. Baseline was defined as the first clinical visit at the Modena Long COVID Clinic, while the follow-up corresponded to the date when the participant completed the online questionnaire.

All data were extracted from electronic medical records and the online survey in full compliance with Italian data protection laws and the ethical approval granted by the Area Vasta Nord Emilia-Romagna Ethics Committee (study approval 396/2020/OSS/AOUMO – Cov-2 MO-Study) and it was in accordance with the Declaration of Helsinki.

Online Questionnaire

The structured online questionnaire comprised five main sections. The first section collected demographic information, and the second gathered medical history, including confirmed Long COVID diagnosis, number of clinic visits, and specialist consultations in the past year.

The third section explored symptoms, diagnoses, therapies, and quality of life, assessing nine Long COVID symptom clusters: respiratory, musculoskeletal, neurocognitive, psychological, autonomic, gastrointestinal, dermatologic, sensory, and other. For each cluster, participants indicated whether symptoms had improved, worsened, or remained unchanged since the previous clinic visit. Additional questions assessed new post-COVID diagnoses, ongoing therapies, and health-related quality of life using the EQ-5D-5L and EQ-VAS (visual analogue scale) questionnaires, asking respondents to rate their general health status (0–100) and whether it had improved, worsened, or remained stable compared to the previous year. The EQ-5D-5L evaluated mobility, self-care, usual activities, pain/discomfort, and anxiety/depression across five levels (no problems to extreme problems) [14]. Optimal quality of life was defined as an EQ-5D-5L score >89.7%, based on reference data from the general Spanish population, chosen for its socio-economic comparability with Italy.

The fourth section assessed perceived needs (met and unmet) through a list of services grouped into four domains: clinical, mental health, social/welfare, and lifestyle. For each service, respondents indicated whether it was received, not received despite need, not sought, not known, or not necessary.

The fifth section explored perceived understanding and support from family, healthcare providers, and the workplace, as well as the personal impact of Long COVID and future expectations regarding health evolution.

The questionnaire was developed by a multidisciplinary team and piloted for clarity among 10 patients before distribution. The English translation of the complete structured questionnaire used for data collection is available as Supplementary Material (Annex 1).

Study outcomes

The primary outcome of the study was derived from Sections 4 and 5 of the questionnaire**,** which explored met and unmet needs across four main domains: (i) clinical care; (ii) mental health; (iii) social and welfare services,

and lifestyle support, as well as (iv) participants' perceived understanding and support from family, healthcare providers, and the workplace.

The secondary outcomes**,** corresponding to Section 3 of the questionnaire**,** included variations in Long COVID symptom clusters and in health-related quality of life (HR-QoL) between the baseline clinical assessment and the follow-up survey.[14]

Statistical Analysis

Continuous variables with normal distribution were expressed as mean ± standard deviation (SD); non-normally distributed variables as median and interquartile range (IQR); and categorical variables as absolute frequencies and percentages. Differences between groups were assessed using Kruskal-Wallis tests for non-parametric data, and the Chi-square test for categorical variables. All analyses were performed using standard statistical software, with significance set at $p<0.05$, using R software.

Results

Of 707 individuals contacted by e-mail, 162 (22.9%) participants completed the online survey (median age 56 years; 89 [54.9%] male). 133 (80.1%) survey responders reported at least one Long COVID symptom cluster. When compared to information collected at the last available clinical visit (baseline), a significant increase was observed in the prevalence of most clusters (Table 1). The median time between the baseline (last clinical evaluation) and the follow-up survey was 3 (Q1, Q3: 0.2, 5.1) years. Compared with non-respondents, individuals who completed the survey were younger (median age 56 vs 61 years, $p<0.001$), while the proportion of male sex was similar between the two groups (54.9% vs 56.0%, $p=0.82$). No significant differences were observed in the prevalence of Long COVID symptom clusters at baseline. However, non-respondents had a longer follow-up time (3.78 vs 2.98 years, $p=0.002$) (Supplementary Table 1).

The musculoskeletal cluster rose from 30.1% to 60.8% ($p<0.001$), the neurocognitive cluster from 23.5% to 52.4% ($p<0.001$), and the psychological cluster from 25.3% to 51.2% ($p<0.001$). The autonomic, gastrointestinal, dermatologic, and sensory clusters also showed significant increases, whereas the respiratory cluster remained stable (47.6% vs 46.4%, $p=0.782$). Table 1 shows patient demographic and cluster prevalence at baseline and follow up.

Alluvial plots (Figure 1A, panels 1–4) illustrate the dynamic transitions of each cluster between baseline and follow-up: a relevant proportion of participants who were asymptomatic for a given cluster at baseline developed new symptoms at follow-up. New onset was most frequent in the musculoskeletal (41.3%), neurocognitive (36.5%), and psychological (35.9%) clusters.

Quality of Life and Self-Rated Health

No significant changes were observed in the overall EQ-5D-5L index score or its individual domains, except for anxiety/depression, which showed a slight but significant worsening (median 1.0 [0.8–1.0] vs 0.8 [0.8–1.0]; p=0.049). Conversely, self-rated health improved significantly from a median of 60 (IQR 50–80) at baseline to 70 (IQR 60–85) at follow-up (p<0.001), suggesting a discrepancy between clinical deterioration and perceived well-being (Figure 1B, radar plot).

Unmet Needs

Survey responses revealed substantial unmet clinical and psychosocial needs. For clinical services (Figure 2A), 43.8% of participants reported receiving pharmacological management for symptoms, while 14.2% reported unmet needs. Diagnostic testing was performed in 48.8% of cases, with unmet needs in 22.2%, and 49.4% received appropriate specialist consultations, yet 22.2% still reported unmet needs.

For mental health services (Figure 2B), coverage was generally poor. Support for loneliness/isolation and relationship counselling was received by only 4.3% and 2.5%, with unmet needs of 11.2% and 12.4%, respectively. Sexual health support was provided to 3.1% (unmet needs 16.0%), stress management to 10.5% (unmet needs 25.8%), and psychological or counselling support to 17.9% (unmet needs 15.4%).

Welfare and lifestyle services are shown in Figure 3A. Most participants did not consider welfare assistance necessary. For lifestyle support, alcohol-related interventions were not used by any participant, smoking cessation support was received by only 0.5%, and pain management emerged as the most frequently used service (9.3%) but also the one with the highest unmet need (15.5%).

When stratified by sex, relevant differences in unmet needs emerged. Women more frequently reported unmet needs in key clinical domains, including

access to specialist visits (31.5% vs 12.4% in men), diagnostic testing (31.5% vs 14.6%), and pain management (24.7% vs 11.2%). In the mental health domain, unmet need for stress management was also higher among women (34.2% vs 19.1%) (Supplementary figure 1-3).

Perceived Understanding and Future Expectations

Perceived understanding (Figure 3B) revealed that 9.8% of respondents felt “poorly” or “not at all” understood by family members, 16.0% by general practitioners, 14.8% by specialists, and 19.0% in the workplace, indicating a substantial perception of lack of recognition and empathy.

Figure 4 summarizes reported consequences and expectations. Lifestyle changes were the most frequently cited effect of Long COVID (26.0%), while social exclusion was reported by 2.5%. Regarding expectations, 21.6% anticipated no change, 9.9% expected worsening, 25.9% were uncertain, and 35.8% expected improvement, reflecting moderate optimism about recovery.

Discussion

This study offers longitudinal, patient-reported evaluations of evolving Long COVID needs within a real-world multidisciplinary clinic through a structured survey. The findings confirm that a considerable proportion of participants reported both clinical and psychosocial needs that were not met. Despite the existence of dedicated post-COVID pathways, barriers to accessing care remain. Participants reported difficulty obtaining specialist consultations, diagnostic procedures, and adequate pharmacological management, highlighting that structural gaps persist in service provision. The situation was even more pronounced for psychosocial support, with only a minority able to access counseling or mental health services, despite reporting significant difficulties. These findings confirm previous evidence that Long COVID is associated with fragmented care and inconsistent service delivery [15].

Mental health was particularly affected. Anxiety and depression worsened over time, which may reflect not only the direct burden of Long COVID but also the lack of dedicated services to address these problems. Depressive and anxiety symptoms remain elevated and worsen over time in Long COVID patients compared to those with short COVID, highlighting the need for integrated psychological support in post-COVID care [16]. Similarly, another study showed persistent mental health deficits in Long COVID patients up to 3.5 years post-infection, with depressive symptoms remaining significantly

higher than in those without Long COVID [17]. This observation is consistent with evidence that patients with unmet social needs are at higher risk of developing severe Long COVID symptoms and neuropsychiatric sequelae [18]. The worsening of psychological symptoms in the absence of structured mental health pathways reinforces the call for integrating psychological support into post-COVID care, a gap repeatedly identified in longitudinal studies [19]. The American Psychiatric Association's 2024 resource document recommends comprehensive treatment planning, including psychotherapeutic and pharmacological interventions for mood and anxiety symptoms in Long COVID, and emphasizes the importance of structured mental health pathways [20]. Additionally, cognitive behavioral therapy and combined physical/mental health rehabilitation may improve depression and overall health in Long COVID patients, supporting the integration of psychological support into care models [21].

Participants also reported high levels of perceived stigma from family members, colleagues, and healthcare professionals alike, reflecting widespread misunderstanding and skepticism about the legitimacy of Long COVID symptoms. Such stigma has been shown to exacerbate psychological distress, delay help-seeking, and erode trust in healthcare systems [22,23]. The combination of unmet clinical needs and social invalidation underscores the urgent need for educational initiatives targeting both the public and healthcare providers to foster recognition, empathy, and equitable access to care.

Furthermore, sex-stratified analyses showed that women reported a higher burden of unmet needs, particularly in relation to specialist care, diagnostic testing, pain management, and stress management. These findings are notable given that Long COVID has been shown to disproportionately affect women, suggesting a potential mismatch between disease burden and access to appropriate care [24,25]. This may reflect differences in symptom perception, healthcare-seeking behavior, or potential disparities in care delivery that warrant further investigation. These results highlight the importance of incorporating a sex-sensitive approach in the design of Long COVID services, ensuring that care pathways adequately address the specific needs of women, particularly in domains related to pain, mental health, and access to specialized care.

A secondary aim of this study was to examine the progression of symptom clusters. At follow-up, nearly four out of five participants (80%) reported at

least one Long COVID cluster, with marked increases in musculoskeletal, neurocognitive, psychological, autonomic, and gastrointestinal domains. The persistence and diversification of symptoms over time indicate that Long COVID cannot be managed as a static condition, but rather as a dynamic, multisystemic syndrome requiring adaptive, cluster-oriented care pathways. These findings align with previous literature reporting sustained symptom prevalence beyond 12 months, particularly fatigue, cognitive dysfunction, dyspnea, and sleep disturbance, affecting 20–40% of individuals depending on the cohort and follow-up duration [26–28].

Interestingly, while symptom clusters increased over time, overall health-related quality of life remained largely stable across domains such as mobility, self-care, usual activities, and pain/discomfort. The only notable deterioration was in anxiety and depression, whereas self-rated health improved slightly. The observed discrepancy between increasing symptom burden and stable quality of life warrants careful interpretation. This finding may partly reflect methodological differences between baseline and follow-up assessments, as symptoms at baseline were collected during clinician-led visits, whereas follow-up data were self-reported through a structured survey. The latter approach may enhance symptom recognition by prompting patients to systematically consider predefined symptom clusters. At the same time, Long COVID is increasingly recognized as a dynamic and evolving condition, with fluctuating symptoms and the potential emergence of new manifestations over time. Taken together, these findings suggest that while symptom burden may increase, perceived well-being can remain stable or even improve through adaptation, coping strategies, and effective symptom management. his interpretation is supported by the observed improvement in self-rated health and aligns with the hypothesis that rehabilitation and education interventions, as well as psychosocial support, may enhance patient autonomy even in the absence of full symptom resolution. Similar observations have been reported by Greenhalgh et al. (2024), who emphasized the importance of combining clinical, psychological, and lifestyle interventions in integrated Long COVID care [10]. A Canadian study exploring social determinants of health in people with Long COVID reported profound impairment of quality of life, with most participants experiencing difficulties in daily activities, mobility, or mental health, while self-care was relatively preserved [29].

Drawing from the unmet needs and overall wellbeing in this survey, a reorientation of clinical services should be considered, guided by the principle of living with Long COVID rather than solely seeking cure. The future Long

COVID Clinic should integrate a cluster-based, patient-centered, and adaptive model that evolves with patients' needs. Key elements include: (i) Comprehensive intake and functional triage: a single-entry point with cluster-based assessment (respiratory, musculoskeletal/pain, neurocognitive, psychological, autonomic/POTS, gastrointestinal, dermatologic, sensory) and personalized goal setting; (ii) Educational and coaching program ("Living with Long COVID"): structured therapeutic education focusing on pacing, heart rate monitoring, sleep quality, cognitive strategies, and energy management; (iii) Specialized cluster clinics: dedicated modules for POTS/dysautonomia, neurocognitive dysfunction, musculoskeletal pain, and psychological support, complemented by quick-access pathways for gastrointestinal, dermatologic, and sensory symptoms; (iv) Case management and continuity of care: a care coordinator to monitor progress, identify symptom fluctuation, and adjust care plans between visits; (v) Outcome measurement: standardized monitoring using EQ-5D-5L, self-rated health, fatigue, anxiety and depression scales and autonomic symptom assessments. Table 2 shows that a new model of Long COVID care should be structured around five operational pillars, emphasizing empowerment, continuity, and real-world improvement in quality of life rather than exclusive symptom eradication.

Importantly, the development and implementation of such care models should incorporate co-design approaches involving people with lived experience of Long COVID. Participatory methods enable the integration of patient perspectives, preferences, and priorities into service design, ensuring that care pathways are not only clinically appropriate but also responsive to real-world needs. Recent studies have demonstrated that co-designed healthcare interventions can enhance patient engagement, improve service accessibility, and better address unmet needs in complex chronic conditions [30,31]. Embedding co-design principles within Long COVID care pathways may therefore represent a critical step toward achieving truly patient-centered and adaptive models of care.

Strengths of this study include its structured and comprehensive assessment of clinical, psychological, and welfare-related needs, as well as the integration of longitudinal data on symptom clusters and quality of life. It offers meaningful insight into patient priorities and lived experiences, providing actionable information for redesigning Long COVID services. The study also contextualizes the observed prevalence of unmet needs within an affluent region, underscoring how these findings may underestimate the burden in less advantaged populations.

Limitations should also be acknowledged. First, the response rate was low, introducing substantial selection bias and likely overrepresenting symptomatic individuals. The low response rate introduces the potential for selection bias. Although respondents and non-respondents were comparable in terms of sex distribution and baseline symptom clusters, respondents were younger and had a shorter follow-up duration. This may indicate that older individuals or those with a longer disease course were underrepresented in the survey. As a result, the findings may primarily reflect the experiences and perceived needs of a relatively younger and more engaged subgroup of patients, and caution is warranted when generalizing these results to the broader population of individuals living with Long COVID. Also, the high proportion of non-response for certain survey items, particularly those presented at the end of the questionnaire, may reflect respondent fatigue or limited suitability of predefined response options. Second, the study was not designed to describe the natural history of Long COVID but rather to capture patient-reported priorities and unmet needs, which influences the interpretation of findings. Third, reliance on self-reported data collected through an online survey may introduce recall and reporting bias, particularly given differences in symptom assessment methods between baseline (clinician-administered) and follow-up (self-reported). Fourth, participants were self-selected individuals already engaged in outpatient care and able to respond via email, excluding those with fewer resources, greater disability, or limited digital access. Fifth, recruitment from a single geographical area limits generalizability to other regions or health systems. Sixth, the absence of a control group restricts the ability to determine whether unmet needs are specific to Long COVID or also found in the general population. Additionally, given that Long COVID has been consistently reported to be more prevalent among women [24,25], the slightly higher proportion of men in our cohort represents a potential limitation. Although sex distribution did not differ between respondents and non-respondents, this imbalance may affect the generalizability of the findings and suggests that the experiences and needs of women with Long COVID may be underrepresented. Finally, because those unfamiliar with technology were less likely to participate, the true prevalence of unmet needs, particularly in disadvantaged groups, may be underestimated.

This study highlights that the most pressing need for people with Long COVID is not the search for a definitive diagnostic test but the acquisition of tools to live better with a fluctuating, multisystemic condition. Redesigning care around symptom clusters, self-management, and continuous follow-up can

improve perceived health and psychological well-being, even when overall disability remains stable. A patient-centered Long COVID Clinic, structured on these principles, can represent a realistic and effective model to address the long-term impact of this condition.

Abbreviations

COVID-19 – Coronavirus Disease 2019; EQ-5D-5L – EuroQol 5-Dimension 5-Level questionnaire; EQ-VAS – EuroQol Visual Analogue Scale; HR-QoL – Health-Related Quality of Life; IQR – Interquartile Range; PASC – Post-Acute Sequelae of SARS-CoV-2 Infection; POTS – Postural Orthostatic Tachycardia Syndrome; PTSD – Post-Traumatic Stress Disorder; SARS-CoV-2 – Severe Acute Respiratory Syndrome Coronavirus 2; SD – Standard Deviation; WHO – World Health Organization

Ethics Approval and Consent to Participate

Written consent was deemed unnecessary, according to the general Authorization to the processing of personal data carried out for purposes of scientific research issued by the Italian Authority for personal data protection (G.U. n. 72 of 26 March 2012). All data were extracted from electronic medical records and the online survey in full compliance with Italian data protection laws and the ethical approval granted by the Area Vasta Nord Emilia-Romagna Ethics Committee (study approval 396/2020/OSS/AOUMO – Cov-2 MO-Study) and it was in accordance with the Declaration of Helsinki.

Consent for Publication

Not applicable.

Availability of data and materials

The datasets generated during and/or analyzed during the current study are not publicly available, but are available from the corresponding author on reasonable request.

Competing interests

Authors did not report any conflict of interest.

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Authors’ contributions

JM, AP and GG conceptualized and designed the manuscript. JM and GG wrote and revised the manuscript. JM did the statistical analysis. JM, CM and GG did the supervision of the final version of the manuscript. LG, TA, MR, MM, GC, GM and CM contributed to discussion and revised the manuscript.

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Table 1. Prevalence of most common symptoms clusters at baseline and follow-up.

Variable	**Baseline (clinical visit)**	**Follow-up (survey)**	**p**
Long Covid			
Respiratory cluster, N (%)	79 (47.6%)	77 (46.4%)	0.782
Musculoskeletal cluster, N (%)	50 (30.1%)	101 (60.8%)	**<0.001**
Neurocognitive cluster, N (%)	39 (23.5%)	87 (52.4%)	**<0.001**
Psychological cluster, N (%)	42 (25.3%)	85 (51.2%)	**<0.001**
Autonomic cluster, N (%)	19 (11.4%)	69 (41.6%)	**<0.001**
Gastrointestinal cluster, N (%)	6 (3.6%)	44 (26.5%)	**<0.001**
Dermatological cluster, N (%)	28 (16.9%)	60 (36.1%)	**<0.001**
Sensory cluster, N (%)	36 (21.7%)	57 (34.3%)	**0.036**
Other cluster, N (%)	9 (5.4%)	34 (20.5%)	**<0.001**
Any cluster, N (%)	109 (65.7%)	133 (80.1%)	**<0.001**

Table 2. Operational pillars to build **a Patient-Centered** new model of Long COVID care

Pillar	**Core Concept**	**Operational Elements**	**Expected Outcome**
1. Functional Triage	Identify symptom clusters and functional goals	Multidisciplinary intake, cluster-based triage	Personalized treatment trajectory
2. Empowerment & Education	Build patient autonomy and coping skills	Pacing, energy management, heart rate monitoring	Improved self-rated health and mental well-being
3. Integrated Cluster Clinics	Deliver coordinated, symptom-specific care	POTS/disautonomia, neurocognitive, musculoskeletal/pain, psychological, and minor clusters	Reduced fragmentation of care
4. Continuity & Case Management	Ensure iterative and adaptive follow-up	Care coordination, symptom tracking, telecoaching	Early recognition of relapses and timely adjustments
5. Outcome-Based Evaluation	Measure what matters to patients	EQ-5D-5L, HR-QoL, fatigue, mental health, goal attainment	Data-driven quality improvement

Figure 1A–B: Symptom cluster variation and QoL/radar plot

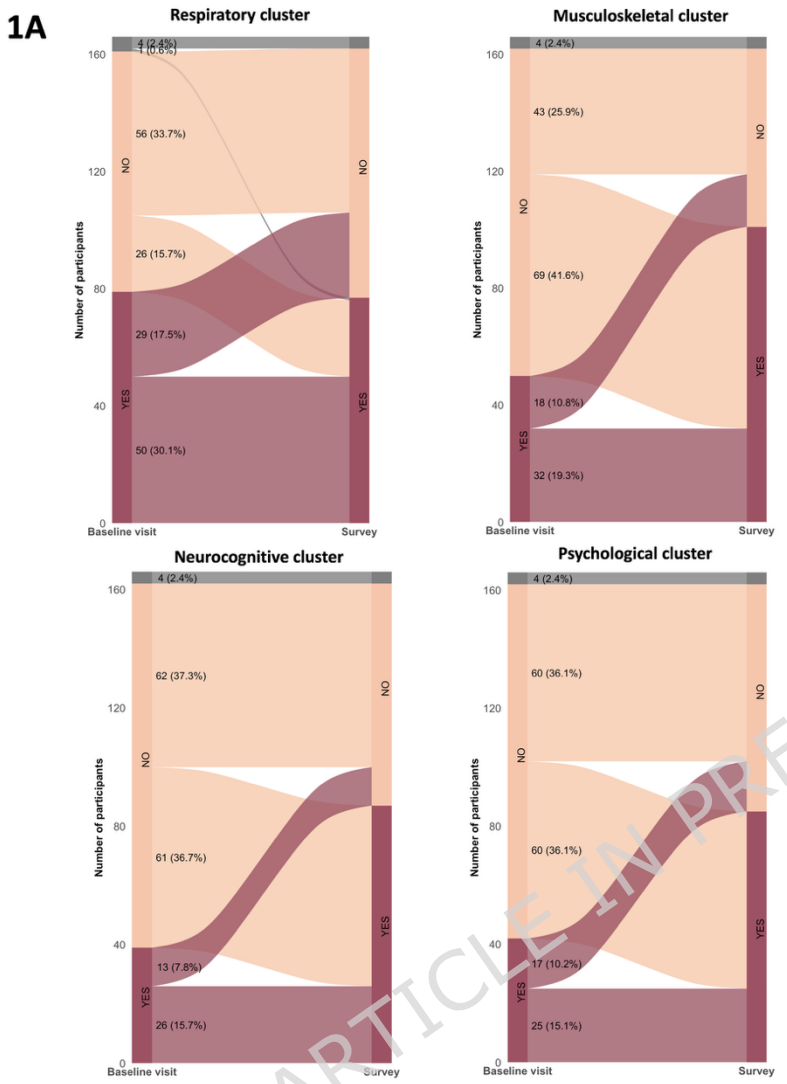


Figure 2A–B: Unmet needs – clinical and mental health services

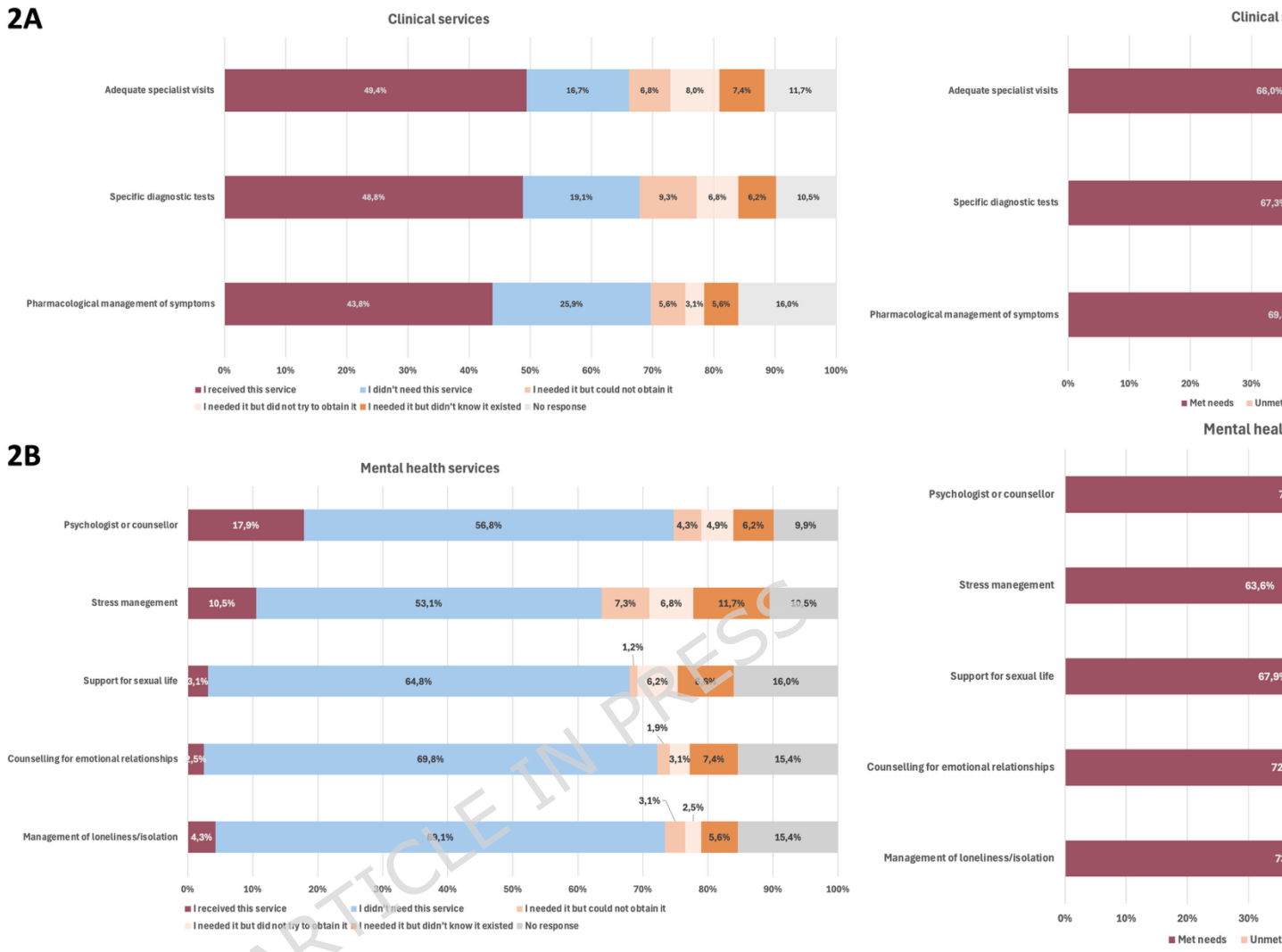


Figure 3A–B: Unmet needs – welfare/lifestyle services and perceived understanding

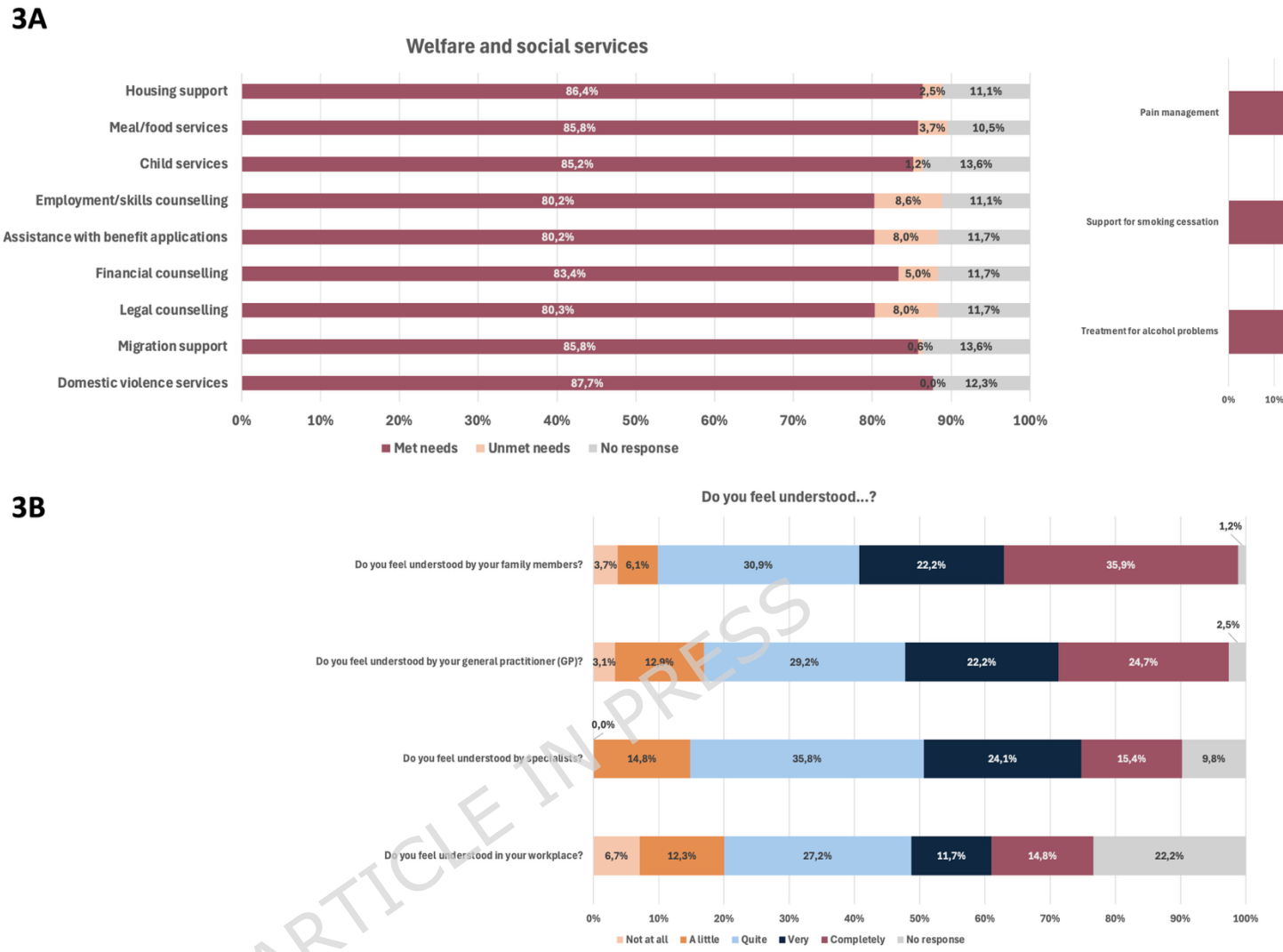
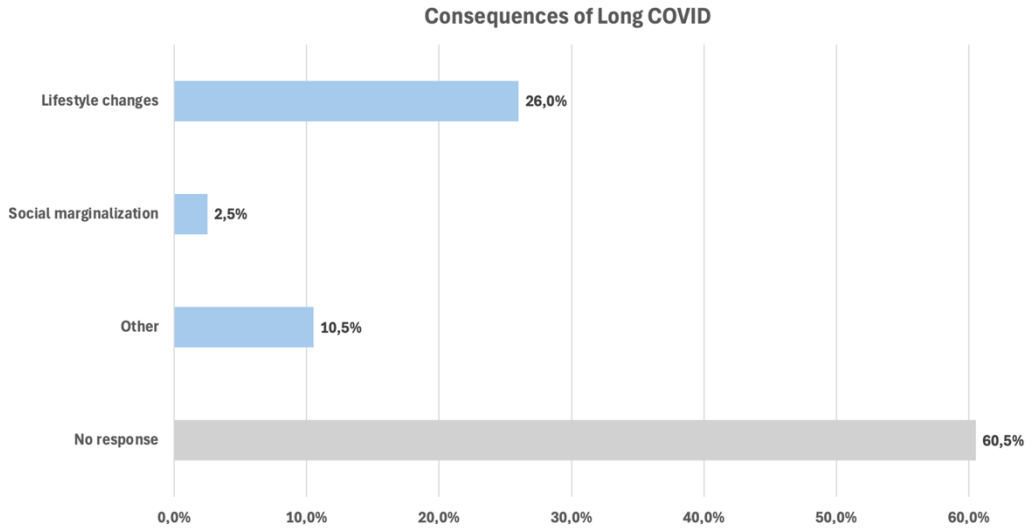


Figure 4: Consequences and expectations

4A



4B