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Research article

Evaluation of doctor-patient interaction and care structure from the perspective of long-COVID and post-COVID patients: a qualitative study with 179 long-COVID patients in Germany

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Abstract: To investigate doctor–patient interactions and care from the patient's perspective, qualitative data from interviews with $N = 179$ long-COVID patients were analyzed and compared with existing guidelines. The findings revealed that most patients expressed dissatisfaction with their interactions due to a lack of understanding and insufficient information about their symptoms. Communication was often inadequate, leading to feelings of uncertainty. Guideline-compliant treatment of physical symptoms, limited capacity, and insufficient provision of information for further treatment were noteworthy issues. The core problem was not only a lack of knowledge or treatment options, but how uncertainty was managed and communicated. Based on these findings, enhancing patient-centered interactions is essential to facilitate the recovery process through empowerment. This should include implementing training for doctors in interpersonal communication and improving healthcare structures. Future studies should consider dyadic approaches and observational methods to deepen the exploration of discrepancies between external and self-perceptions.

Keywords: Long-COVID; guidelines; treatment; communication

Abbreviations: DPI: doctor patient interaction; PACS: post-acute COVID syndrome; NICE: National Institute for Health and Care Excellence

1. Introduction

The relationship between healthcare professionals and individuals seeking help is crucial for the entire care process, specifically, doctor–patient interactions (DPI). This interaction not only affects patient satisfaction and treatment adherence but also impacts a patient's physical and mental health, as well as their recovery trajectory [1]. Previous studies have shown correlations between the type of communication used, patients' socioeconomic situations, and physicians' communication styles [2,3]. There is evidence that suggests a sustained improvement in a patient's well-being in correlation with subjectively [4] positive evaluations of DPI [5].

If the DPI is inadequate and patients encounter a lack of acceptance or are left to self-medicate [6], this may lead to risky self-management and feelings of helplessness and resignation [7]. Considering the patients perspective provides valuable insights into areas where DPIs could be improved. These primarily concern the perceived communication [8], trust in physicians, and empathy [9]. Empathetic listening is essential to establish a good DPI, as is patient-centered communication, which takes the needs and preferences of patients as holistic individuals into account [10,11]. Both aspects have become more challenging due to protective measures such as face masks and increased online communication [12].

In addition, a summary of long-COVID studies demonstrated informational uncertainties present among both patients and physicians [13]. An in-depth examination of the patient perspective can help develop strategies for improving the DPI [4]. This is particularly significant in the context of chronic and novel diseases. At the beginning of the COVID-19 pandemic, post-COVID/long-COVID represented both categories. For this reason, data from 2022 were analyzed in the present study to address the knowledge gap. According to recent estimates, approximately 10–20% of all people affected by COVID-19 develop post-COVID/long-COVID after infection [14]. Long-COVID is defined as symptoms persisting for more than four weeks after infection, while symptoms that last longer than twelve weeks are classified as post-COVID. If symptoms continue for more than twelve months, the condition is deemed chronic [14,15]. The term PACS (post-acute COVID-19 syndrome) is used herein.

Although various studies have addressed the diagnosis of PACS [16,17] and the assessment of rehabilitation needs and functional limitations [18], there was substantial uncertainty regarding diagnoses and treatment strategies, particularly early in the pandemic. German guidelines (S1 Long/Post-COVID) primarily addressed clinical and practical issues; references to interpersonal communications were limited to the introduction [19]. Moreover, the statement by the German Medical Association solely focused on clarifying physical symptoms [20]. For reference and comparison, this study refers to the guidelines of the National Institute for Health and Care Excellence (NICE) [21], as these, at the time of data collection, were the only known and published guidelines that explicitly provide recommendations for interpersonal behavior and DPIs for PACS patients. The relevant excerpt from these guidelines is shown in Table 1.

Table 1. Excerpt from the NICE guidelines relating to doctor-patient interaction [21].

Recommendations for doctors
1. Provide your patients with information about the most common symptoms and how to manage them. Symptoms are expected to come and go in waves, and new symptoms may appear.
2. Recovery process: Most people recover after 3 months.
3. Self-management: Provide recommendations on who patients should contact if they have complaints or concerns. Explain how to obtain support from other services, e.g., social or financial support.
4. Pay particular attention to people from vulnerable groups (those with pre-existing conditions, dementia, etc.) and allow more time for them.

Care provided by general practitioners is of utmost importance, as they are the first point of contact for patients [22]. Furthermore, PACS diagnosis and treatment must be multidisciplinary, interprofessional, and individualized [23], as it can lead to uncertainty for both patients and practitioners and consequently affect the DPI [24]. Evaluating care with a focus on patient perception is crucial for identifying obstacles and developing strategies for improvement [25]. To address these issues, the present study evaluated a patient's perceptions of the DPI and medical care in PACS, comparing them to existing guidelines.

The research questions are as follows:

1. How were the interactions and care experienced by patients?
2. To what extent are the patient's reported experiences consistent with key recommendations of the published PACS guidelines?

2. Method

Ethical approval was granted by the Ethics Committee of Jacobs University Bremen (Application No.: 2021_08). The project was registered on ClinicalTrials.gov (NCT05238415). All participants were informed about the study and invited to give written consent. Only those who provided written consent were included. All data were pseudonymized.

2.1. Data collection

The ASAP project, within which the data for this study were collected, has been described in detail elsewhere [26]. Data for the present study were generated using semi-structured telephone interviews conducted by various interviewers. The development of the interview guide can be reviewed in publications which focused on the ASAP project [26] (also, see interview guidelines attached). Verbal responses were not recorded, but documented in writing by the personal pilots using an online tool [26]. Answers to open questions were documented word by word, "Yes" or "No" Answers, and facts indicated accordingly. All transcripts were anonymized by one researcher and analyzed for content using the Excel software.

2.2. Participants, data preparation, and qualitative analysis

Only individuals who had been confirmed as PACS patients through online screening were included. Data from a total of $N = 179$ patients were analyzed. All participants resided in Bavaria and none were admitted to medical rehabilitation or had a longer hospitalization history, as this was an

inclusion criterion [26]. In total, 126 female (70.4%) and 51 male (28.5%) individuals participated in the study; the remaining ones either classified themselves as diverse or did not indicate their gender. The mean age was M = 44.4 years (SD = 12.0, Range 20–61). 97 individuals (54.5%) reported pre-existing conditions, while 81 individuals (45.5%) reported none. As an indication of the severity of illness, 3 months after the interview, we assessed whether individuals applied for a disability pension because of severe limitations in their functionality. Forty-three (24.2%) replied that they applied accordingly, while 70 (39.3%) replied that they did not apply. All remaining individuals did not answer this question.

In the first interview within the ASAP study, the participants were asked about their previous medical care: "Have you received medical care for your long-COVID symptoms (after hospital discharge or in connection with your illness)?" The participants could answer "yes" or "no" and provide further comments. Those who only described the type of care, denied receiving care, or did not comment were excluded; thus, the qualitative analysis included N = 170 patients (see Figure 1).

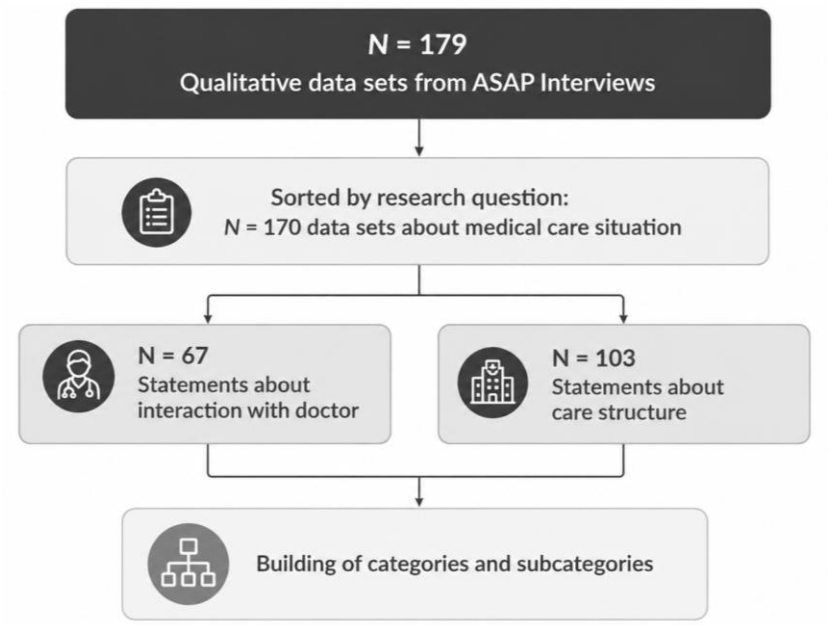


Figure 1. Procedure of data analysis.

Qualitative data were analyzed using an inductive qualitative content analysis following the Schreier and Weydmann's approach [27]. Consistent with the category-oriented and systematic nature of the qualitative content analysis, the interview transcripts were segmented into meaning units defined as coherent text passages ranging from a phrase to several sentences that expressed a single idea or experience relevant to the research questions [28]. Text segments were considered relevant when they contained information related to the participant's experiences, perceptions, evaluations, or behaviors regarding the phenomena under investigation.

The coding process was conducted by two researchers (SS and SL). To establish a shared understanding of the coding framework, both researchers independently coded approximately 5% of the interview material and subsequently compared and discussed their coding decisions. Based on this process, a preliminary coding frame was jointly developed. The categories and subcategories were

inductively generated from the data through an iterative process of comparison, abstraction, and data reduction. After agreement on the coding frame was reached, the remaining interviews were coded using the refined framework. Both researchers remained involved throughout the analytic process through regular meetings in which the coding decisions, category definitions, and emerging interpretations were reviewed and discussed. Disagreements in coding were resolved through discussions and consensus.

The coding frame was continuously reviewed and refined during the analysis to ensure conceptual clarity, mutual exclusivity of categories, and alignment with the study objectives, which is consistent with recommendations for a qualitative content analysis and coding frame development [29,30]. To enhance trustworthiness, the coding decisions, category revisions, and analytic reflections were documented throughout the analysis process, creating an audit trail and allowing continuous reflection on the category definitions and coding consistency [31,32].

Rather than applying a purposeful sampling strategy with interview partners, the analysis involved relevance-based selection of meaning units within the interview material [30]. Following Schreier and Weydmann's emphasis on the systematic and research question-driven analysis, only text segments that directly addressed the study aims were included in the coding process (see Figure 2). This approach focused the analysis on content that contributed to understanding the phenomena under investigation while retaining the broader interview context when required for interpretation. As the participants underwent multiple interviews with recurring questions (see [26]), emerging categories and themes could be examined across repeated measurement points.

The adequacy of the category system was assessed throughout the analytic process by monitoring whether newly analyzed interviews generated additional categories or required substantial modification of existing categories. No substantively new categories emerged after the analysis of the first 4 interviews representing approximately 2% of the dataset. Subsequent interviews confirmed the existing category structure and only led to minor refinements of the category descriptions. This pattern was interpreted as evidence of *thematic saturation* and sufficient conceptual depth of the coding framework [27,28].

This iterative analytic process facilitated both thematic saturation and conceptual depth, with later interviews confirming and refining existing concepts rather than introducing new categories, thus supporting the adequacy and completeness of the findings.

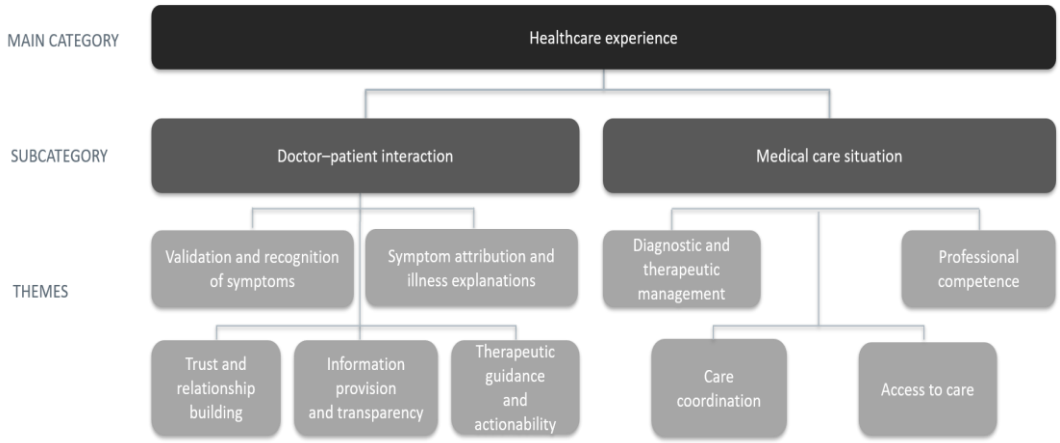


Figure 2. Main and subcategories formed from the data of the $N = 170$ interviews.

3. Results

Two major categories were derived from the qualitative data regarding emotions and cognitions about medical care reported by $N = 170$ patients: (1) statements regarding direct interactions with the doctor and (2) statements regarding the general care situation. Then, differentiated subcategories were formed (see Figure 2). The following sections summarize these statements to address research question 1: how were the interactions and care experienced by patients in 2022?

The full results are shown in Table 2.

Table 2. Overview of themes within the subcategory DPIs identified in the qualitative analysis.

Themes	Definitions and patients reports	Patients (% of statements)
Theme 1: Understanding, validation and recognition of symptoms	Definition: How far patients felt their symptoms and concerns were acknowledged, legitimized, and taken seriously.	
	Feels "not taken seriously"	18 (27%)
	Medical professionals explained the symptoms in other ways, for example, attributing "all symptoms to the psyche" or "stress"	8 (12%)
	Feels "dismissed," appeased, or portrayed as unimportant ("We have a waiting room full of cases like yours here")	8 (12%)
	"looked at strangely" when expressing their own suspicion of PACS	1 (1.5%)
	felt better cared for by alternative practitioners, such as naturopaths ("The family doctor said nothing more than 'psychologist'"; "only the naturopath took me seriously")	1 (1.5%)
Theme 2: Symptom attribution and illness explanations	Definition: How physicians explained symptoms and whether these explanations were perceived as plausible and acceptable.	
	Good understanding and "taken seriously" by doctors	6 (9%)
	Good effort to help further	7 (10.4%)
	Feeling "well cared for" or "in good hands"	6 (9%)
Theme 3: Information provision and transparency	Definition: Communication concerning diagnosis, prognosis, disease mechanisms, and expected illness course	
	Lack of knowledge on the part of doctors regarding diagnosis and treatment options ["My doctor simply had no more ideas"; "did not make the connection to LC (long-COVID) when asked"; "helplessness" and "lack of knowledge"; patients received conflicting recommendations from primary care providers and other practitioners – such as "do sports" on the one hand and "take sick leave and rest" on the other]	39 (37.8%)
Theme 4: Trust and relationship building/communication	Definition: How communication affected confidence in healthcare providers.	
	Patients missed being given information about their illness or its progression	7 (10.4%)
	Found the treatment options mentioned to be insufficient ("wait and see"; "only investigate the causes"; "no instructions for action without findings")	12 (17.9%)
	Patients who were more satisfied with the interaction	15 (22.4%)
Theme 5: Therapeutic guidance and actionability	Definition: Communication aimed at helping patients understand what to do next.	
Appointments	Problems getting into a secondary care structure at all, as there were "no appointments" or "very long waiting times"	18 (17.4%)

Continued on next page

Themes	Definitions and patients reports	Patients (% of statements)
Treatment	Received medication to relieve symptoms	34 (33%)
	Received sick leave or advice to "recover"	17 (16.5%)
	Blood sampling, PCR test, and lung and heart function tests	30 (29.1%)
	Referrals or direct treatment by a specialist	76 (73.8%)
	Examination and further treatment by a cardiologist or pulmonologist	36 (34.9%)
	Neurological examinations	16 (15.5%)
	Referred to ENT specialists	6 (5.8%)
	Referred to internists	3 (2.9%)
	Referred to psychologists	3 (2.9%)
	Referred to rehabilitation	2 (1.9%)

Note: Reported frequencies represent the number of participants mentioning a given experience at least once. Percentages are calculated based on the number of statements regarding interaction with a doctor (67) and statements about care structure (103), rather than the total number of coded statements (Figure 1). Multiple responses per participant were possible.

3.1. Subcategory: Interaction with the doctor

The analysis of the patient reports identified five communication-related themes: (1) validation and recognition of symptoms, (2) symptom attribution and illness explanations, (3) information provision and transparency, (4) trust and relationship building, and (5) therapeutic guidance and actionability. Across all themes, the patients emphasized the importance of feeling heard, receiving understandable explanations, and obtaining clear guidance regarding symptom management.

The dominant theme was validation and recognition of symptoms. Many patients described interactions in which they did not feel that their symptoms were adequately acknowledged or legitimized. Eighteen patients explicitly reported not being "taken seriously," while others described feeling dismissed, appeased, or portrayed as unimportant. These experiences were often connected to perceptions that healthcare professionals lacked an understanding of the severity and impact of their symptoms.

A closely related theme concerned symptom attribution and illness explanations. Several patients reported that physicians primarily attributed their complaints to psychological causes or stress rather than considering PACS as a potential explanation. One participant reported being "looked at strangely" when suggesting PACS as the cause of their symptoms. Such experiences suggest a mismatch between a patient's own interpretations of their condition and the explanations provided by healthcare professionals.

Additionally, the patients highlighted shortcomings in information provision and transparency. Several participants reported receiving insufficient information about their illness, its progression, or expected recovery. In addition, a lack of explanation regarding the available treatment options contributed to feelings of uncertainty about disease management.

Furthermore, communication experiences influenced trust and relationship building. Some participants indicated that they felt better cared for by alternative practitioners, such as naturopaths, whom they perceived as more willing to acknowledge their symptoms and concerns. In contrast, a minority of patients described positive interactions with physicians, emphasizing their efforts to help, their understanding of the condition, and their willingness to continue searching for solutions. Six participants reported feeling "well cared for" or "in good hands." These accounts suggest that patient satisfaction was closely linked to experiences of validation, engagement, and perceived commitment by healthcare professionals, even when the treatment options remained limited. The findings suggest

that patients valued relational continuity, that is, the experience that a physician remained involved and supportive despite the absence of clear treatment pathways. For chronic and poorly understood conditions such as PACS, continuity may represent a therapeutic resource in its own right, reducing feelings of abandonment and enhancing trust.

Finally, the theme of therapeutic guidance and actionability was reflected in reports that consultations often resulted in non-specific recommendations such as "wait and see" or further investigations without clear instructions for symptom management. The patients frequently expressed a desire for more concrete advice and guidance on how to cope with their condition.

3.2. Subcategory: Care situation

Descriptions within this category focused on experiences with the broader healthcare system. The themes emerging were categorized into professional competence, access to care, care coordination, and diagnostic and therapeutic management. In contrast to the interpersonal aspects of communication described above, patients' statements in this category emphasized structural and organizational dimensions of care.

The most prominent theme was professional competence, in the form of uncertainty regarding the PACS diagnosis and treatment. Thirty-nine patients reported that healthcare providers appeared to have limited knowledge of the condition or lacked clear diagnostic and therapeutic strategies. Statements such as "my doctor simply had no more ideas", "helplessness", and "lack of knowledge" reflected the patient's perceptions that many healthcare professionals were struggling to manage a complex and emerging condition. Beyond a lack of expertise, the participants also described uncertainty regarding clinical recommendations, with some reporting conflicting advice from different providers, such as recommendations to engage in physical exercise versus advice to rest and avoid exertion. These experiences contributed to perceptions of inconsistency within the healthcare system.

A second theme concerned access to appropriate care and specialist services. Eighteen patients reported difficulties accessing further medical assessments because of unavailable appointments, long waiting times, or challenges entering specialized care pathways. These barriers frequently delayed diagnostic clarification and further treatment, contributing to frustration and uncertainty regarding disease management.

Additionally, the patients commented on care coordination and referral pathways. Despite difficulties in accessing services, the majority of the participants reported receiving referrals to specialists or undergoing further diagnostic investigations. Seventy-six patients were referred to or treated by specialists, most commonly cardiologists or pulmonologists (N = 36), while others underwent neurological examinations (N = 16) or were referred to ENT specialists, internists, psychologists, or rehabilitation services. These reports suggest that healthcare providers attempted to address symptoms through specialist assessment, although access and continuity of care considerably varied among patients.

Finally, the participants described experiences related to diagnostic and therapeutic management. Most reported receiving symptom-oriented care rather than targeted treatment approaches. Thirty-four patients received medication to alleviate symptoms, and seventeen received sick leave or recommendations to rest and recover. Diagnostic investigations frequently included blood tests, PCR testing, and cardiovascular or pulmonary examinations. Collectively, these findings indicate that care was characterized by extensive diagnostic work-ups and specialist referrals, while patients

simultaneously perceived uncertainty regarding evidence-based treatment options and long-term management strategies.

3.3. Comparison with guidelines on DPI and care for PACS

Research question 2 concerned to the extent to whichpatient's reported experiences were consistent with key recommendations of published PACS guidelines. The reported participant experiences illustrate perceived discrepancies between NICE guideline recommendations and practice. Few patients reported receiving explicit information about symptoms, their frequency, or management strategies. Most received vague advice such as "wait and see" and were not informed about the recovery timelines. Only a few were advised to seek psychological support; empowerment regarding social or financial support was uncommon. The reports indicate no extra time was allocated for interactions with patients who had pre-existing conditions. Thus, from the patient perspective, NICE guideline recommendations on the DPI for PACS were only minimally implemented.

However, with respect to treatment, the majority of patients were diagnosed and stated to be managed (or referred) according to current S1 guidelines.

4. Discussion

This study explored how 170 individuals with PACS experienced medical care during 2022, when the diagnosis was still new and ambiguous for many healthcare professionals. The study had a particular focus on the DPI, alignment with recommendations for diagnosis, and care management. The findings indicate that the patient's experiences were shaped not only by access to diagnostic and specialist services but, more substantially, by how they perceived healthcare professionals' communication of uncertainty, acknowledgment of symptoms, and provision of guidance for disease management.

4.1. Communication and the need for symptom validation

A central finding was the importance of symptom validation. Many participants reported feeling that their symptoms were not taken seriously, were minimized, or were primarily attributed to psychological causes or stress. In contrast, positive experiences were characterized by physicians acknowledging symptoms, listening attentively, and demonstrating a willingness to continue supporting patients despite limited treatment options.

These findings are consistent with previous research on Long-COVID, which has identified experiences of disbelief, stigmatization, and diagnostic invalidation as common challenges [1,2,5]. Patients frequently report that the absence of objective biomarkers and the heterogeneity of symptoms can lead to their complaints being questioned or psychologized. Similar findings have been reported in studies from the United Kingdom, Germany, and other European countries [15,16,33], where patients described struggles to have their symptoms recognized as legitimate medical concerns. Such experiences have been shown to negatively affect trust in healthcare services and contribute to feelings of isolation and frustration [7].

One interpretation of our findings is that symptom validation may be more important for patient satisfaction than the availability of specific therapeutic interventions. An important insight from these findings is that dissatisfaction did not appear to solely arise from the absence of effective treatments.

Rather, the findings suggest a mismatch between what healthcare professionals may have perceived as the primary challenge (limited therapeutic options) and what patients expected from consultations (validation, orientation, and partnership despite uncertainty). Patients often appeared willing to accept diagnostic and therapeutic ambiguity when this uncertainty was communicated openly and empathetically. This observation aligns with broader patient-centered care literature which indicates that communication quality and perceived recognition strongly influence healthcare satisfaction, particularly in conditions characterized by uncertainty [7].

4.2. Diagnostic uncertainty and professional competence

The second major theme concerned perceived limitations in professional knowledge about PACS. The participants frequently reported to perceive healthcare professionals as uncertain, overwhelmed, or lacking clear strategies for diagnosis and treatment. Reports of conflicting recommendations regarding exercise, rest, and recovery further reinforced perceptions of inconsistency within the healthcare system. PACS may represent a situation of shared epistemic uncertainty, in which both patients and healthcare professionals lack clear explanations and prognostic certainty. A broader interpretation of these findings suggests that tensions in the doctor-patient relationship may emerge when this uncertainty is interpreted differently by each party. Patients may perceive uncertainty as a lack of recognition or expertise, whereas clinicians may experience it as a consequence of limited scientific evidence.

Our findings must be interpreted in the context of the study period. Data were collected in 2022, when PACS was still an emerging condition and clinical guidance was rapidly evolving. Healthcare professionals were often required to manage patients despite an incomplete evidence base and limited consensus regarding effective interventions. Similar perceptions of professional uncertainty have been internationally documented, with patients reporting difficulties obtaining clear information, coherent treatment recommendations, or coordinated care pathways [9,12].

Importantly, our findings suggest that patients distinguished between uncertainty and incompetence. The participants did not merely criticize the lack of available treatment options; rather, dissatisfaction appeared to arise when uncertainty was insufficiently acknowledged or communicated. Previous research [8,9] has demonstrated that transparent communication regarding medical uncertainty can strengthen trust, whereas contradictory recommendations and unexplained changes in management can undermine confidence in healthcare providers. One interpretation of the findings is that uncertainty itself may not be the primary threat to the doctor-patient relationship in PACS. Rather, relationship difficulties appear to emerge when uncertainty is not explicitly acknowledged or explained. The patients often described positive encounters even when no effective treatment could be offered, whereas negative experiences were frequently associated with poor communication regarding uncertainty. This suggests that the management of uncertainty may be at least as important as reducing uncertainty itself.

4.3. Information provision and actionable guidance

Another important finding was the perceived lack of information regarding illness progression, prognosis, and self-management. Many of the participants described receiving general recommendations such as “wait and see” without sufficiently detailed explanations or practical guidance.

This phenomenon has been frequently reported in Long-COVID research [10,16]. Patients commonly describe uncertainty regarding expected recovery trajectories, symptom fluctuations, and appropriate levels of physical activity. Given the limited evidence available during the early stages of the pandemic, healthcare professionals may have struggled to provide definitive prognostic information. Nevertheless, the present findings suggest that patients were seeking not only medical explanations but also practical support in navigating everyday challenges associated with PACS.

The distinction between information provision and actionability is particularly relevant. While information can reduce uncertainty, patients often require guidance that translates medical knowledge into concrete recommendations for symptom management, work participation, physical activity, and social functioning. Therefore, future models of PACS care should combine diagnostic assessments with structured patient education and self-management support.

4.4. Access to care and healthcare structures

Although communication-related challenges were prominent, the participants also reported significant structural barriers for healthcare. Long waiting times and difficulties obtaining specialist appointments were frequently described. These findings mirror reports from other healthcare systems, where increasing demand for Long-COVID services has often exceeded the available capacity.

Interestingly, despite these access barriers, many participants underwent extensive diagnostic testing and specialist assessments. Most reported referrals to specialist services, particularly cardiology, pulmonology, and neurology. This suggests that healthcare providers generally attempted to investigate persistent symptoms and organize further assessments in accordance with emerging clinical recommendations.

The coexistence of substantial diagnostic work-ups and dissatisfaction with care highlights an important distinction between the technical and relational dimensions of healthcare quality as perceived by patients. The patients frequently received investigations and referrals, yet many still perceived their care as inadequate because communication, validation, and guidance were lacking. These findings reinforce the importance of considering a patient's experiences alongside diagnostic and treatment activities when evaluating the perceived quality of care. The findings suggest that extensive diagnostic activity does not necessarily translate into positive patient experiences. Patients may evaluate care using criteria that extend beyond biomedical investigation, including feeling understood, receiving explanations, and obtaining practical guidance. This distinction may help explain why dissatisfaction can persist even when healthcare professionals actively pursue diagnostic work-ups and specialist referrals.

4.5. Comparison with guideline recommendations

When comparing the patient's reported experiences with NICE recommendations regarding patient-practitioner interaction, several perceived discrepancies emerged. NICE emphasizes validating symptoms, acknowledging uncertainty, providing clear information, involving patients in decision-making, and supporting self-management. In contrast, many participants reported feeling dismissed, receiving insufficient explanations, or lacking practical guidance regarding symptom management and recovery.

At the same time, the findings indicate a greater degree of adherence regarding diagnostic investigations and referral pathways. Many patients described examinations, specialist consultations, and ongoing assessments that were broadly consistent with recommendations contained in national and international PACS guidelines. Thus, from the patient's perspective, guideline-concordant care appeared more evident in biomedical and diagnostic aspects of care than in communication-oriented and supportive components of patient management.

4.6. Possible mechanisms underlying the reported difficulties in doctor-patient interaction

Beyond the issues already described in the Long-COVID literature, the present findings suggest several possible mechanisms. First, PACS consultations often occur in a context of high scientific uncertainty, which may challenge traditional expectations that physicians provide clear diagnoses, prognoses, and treatment plans. Second, patients and physicians may prioritize different consultation outcomes: while physicians may focus on excluding serious pathology and arranging investigations, patients may place greater importance on validation, explanation, and practical guidance. Third, repeated experiences of inconclusive findings may gradually alter a patient's expectations and trust, making subsequent interactions increasingly vulnerable to misunderstanding. These interpretations require further investigation but may help explain why dissatisfaction can persist even when considerable diagnostic effort is undertaken.

4.7. Implications for practice

The findings suggest that improving PACS care may not solely depend on the development of new therapies. Equally important may be strengthening a clinician's communication skills in situations characterized by uncertainty. Explicit symptom validation, transparent discussion of knowledge gaps, clear explanations of diagnostic reasoning, and provision of practical self-management advice may substantially improve a patient's experiences even when treatment options remain limited. Therefore, future PACS services should consider integrating both medical and communication-related competencies as core components of care to improve a patient's experiences.

Regarding care structures, the participants frequently reported experiences suggestive of limited capacity and long waiting times in specialist centers, including outpatient COVID-19 clinics. Some patients reported unsuccessfully searching for support for months, resulting in frustration, perceptions that healthcare professionals lacked sufficient expertise, and sometimes a change of doctor or consultation with alternative practitioners. While the DPI appears highly relevant to the patient's experiences of PACS care, the present findings suggest that many participants perceived shortcomings in this area, indicating a need for improved care models.

Establishing and maintaining PACS-specific care has been—and remains—one of the greatest challenges for the healthcare system, given the patient volumes. Service gaps and information-transfer issues both contribute [22,34]. Some patients develop learned helplessness after prolonged unsuccessful searches for support. Self-empowerment could play a role in counteracting this trend. The following measures and implications are recommended based on these findings.

1. Further develop recommendations for adequate interactions between physicians and PACS patients. This could include expanding current guidelines to address interpersonal communication.

2. Train physicians in interpersonal communication. Efforts should be made to ensure that patients feel their experiences are taken seriously. Where available, information and treatment options, as well as psychological, physical, and social support, should be offered. Patients should be supported in self-advocacy and seen holistically, beyond symptoms relating to a single specialty. The goal should always be patient-centered interaction.

3. Improve care structures. Enhanced networking among clinics, specialists, and outpatient facilities is needed. Expanding specialized centers and advanced diagnostics should be considered essential in post-pandemic care.

Lessons from the COVID-19 pandemic may be transferable to future crises. Since the NICE guidelines are unique in addressing interpersonal communication in PACS, it may be worth considering whether such shortcomings are universal or disease-specific. Both patients and healthcare professionals face significant challenges with both chronic and emerging conditions [7,33]. A lack of knowledge can lead to uncertainty, undermining the doctor–patient relationship [5,6]. The findings suggest that, from the patients' perspective, sustainable improvements in the DPI and care are needed.

5. Limitations and suggestions for future research

Qualitative research inherently involves subjectivity. Documentation may have varied between interviewers—different words might have been used, potentially influencing the meanings ascribed during data reduction. However, patients typically used clear expressions such as "not taken seriously", or the meaning was clear based on the context.

One methodological limitation concerns the absence of audio recordings. First, this procedure increases the risk of selective documentation, potentially introducing bias and affecting the representativeness of the data. Second, the inability to verify transcripts against original recordings limits the transparency and auditability of the data collection process, which are key criteria for establishing credibility and dependability in qualitative research.

Nevertheless, empirical comparisons between audio-recorded transcripts and interview scripts suggest that, under certain conditions, data quality may remain comparable in terms of substantive content captured [35,36]. In this study, several mitigation strategies were employed to ensure that the essential content and key statements of the conversations were validly documented: (1) the interviewer received systematic training in qualitative interviewing techniques; (2) a semi-structured interview guide was used to ensure thematic consistency across interviews; and (3) transcripts were reviewed and immediately refined following each interview to minimize recall bias.

All data reflect the patient's subjective descriptions; there is no objective verification, and the physician's perspectives were not assessed. Future studies might employ mixed methods for quantitative validation, such as assessing the quality of interaction alongside treatment outcomes using tools like the PAINT questionnaire [26].

The patient's perspectives may be shaped by individual mindsets (perception, memory, thought patterns). Including the healthcare professionals and relatives' perspectives would improve understanding of why negative experiences occur and whether the patient's behaviors interrelate with these interactions. Dyadic approaches may help to bridge the gap between external and self-perception, and results should be replicated in other disease contexts. Therefore, further research is warranted. Consequently, the findings should be interpreted as reflecting a patient's perceptions and experiences

of care rather than objectively verified deficiencies in healthcare quality, professional competence, or guideline adherence.

Author contributions

SS, SL and AD conceptualized and designed the study, supervised the project, and drafted the manuscript. SS, RR and CK contributed to study design, collected and curated the data. SS and SL performed data analysis. SS, AD and SL contributed to data interpretation, prepared figures and tables, and critically revised the manuscript. AD and SL acquired funding and provided methodological guidance. All authors read and approved the final version of the manuscript and agree to be accountable for all aspects of the work.

Use of AI tools declaration

The authors declare they have not used Artificial Intelligence (AI) tools in the creation and initial writing process of this article. Co-pilot was used for proofreading and improving readability of the final draft. The authors take full responsibility for the content.

Ethics approval and consent to participate

Ethics approval was granted by the Ethics Committee of Constructor University Bremen (formerly known as Jacobs University Bremen). Application No.: 2021_08. The project was registered on ClinicalTrials.gov (NCT05238415). All participants were informed about the study and invited to give written consent. Only those who provided written consent were included. All data were pseudonymized.

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Conflicts of interest

The authors declare no conflicts of interest.

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