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HAL Authorization

COVID-19 patient experiences in pre-hospital pathways (article 1): a processual approach using the life-events calendar method highlights diagnostic delays and healthcare renunciation.

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Abstract

Background

During the height of the COVID-19 pandemic in 2020, 11% of patients who were hospitalized in France were immediately admitted to intensive care. We aimed to identify and characterize the different types of primary care pathways of patients hospitalized for COVID-19 using patients' self-reported experiences.

Method

We conducted a qualitative study using biographic interviews of patients who were hospitalized for COVID-19 between September 2020 and December 2021 in the infectious disease departments in Marseille and Nice. The biographical interviews used a life-events calendar approach to understand the sequences of clinical and care events prior to hospitalization.

Results

31 pathways were described. Short care pathways (i.e., admission to hospital ≤ 3 days after symptom onset) were more likely to be reported by older patients and those with comorbidities. These pathways were characterized by closer GP surveillance and by sudden symptom onset and rapid progression of the disease.

Long care pathways (i.e., >10 days after system onset) were reported more by younger patients with no comorbidities. Multiple tests and medical consultations returning false-negatives had led this population to doubt they had COVID-19. They were more likely to present severe symptoms requiring intensive care.

The study revealed key importance of patients' loved ones in the process of their hospitalization.

Conclusion

This study highlights that primary care management of COVID-19 patients needing hospitalization in France was particularly slow and detrimental to their health. It also underlines the need to improve the identification and monitoring of patients at risk of complications.

Keywords: patient care management, comprehensive health care, uncertainty, primary health care, COVID-19

Words 4098

INTRODUCTION

The fight against the COVID-19 pandemic continues on several fronts. This fight not only concerns therapeutic advances but also improved clinical management of patients. A national French study conducted between March 2020 and January 2021 showed that nearly 20% of patients with COVID-19 were admitted to a hospital department after consultation in an emergency department (ED), and that 11% of these were immediately admitted to an intensive care unit (ICU)[1]. That study also found that almost all patients admitted to a hospital department had one or more comorbidities. It is possible therefore that for these fragile patients - a group requiring increased primary care (i.e., pre-hospitalization) medical surveillance - their primary care pathway (i.e., in terms of clinical management and the pathway duration) was too slow [2].

A hospital crisis management system can only work if the organization of primary care is effective, especially regarding early referral of patients with a poor prognosis to hospital. To improve COVID-19 primary care management, with a view to improving disease prognosis, it is important to study patients' care pathways preceding hospitalization, particularly those of patients admitted immediately to an ICU [3].

France's National Health Data System (SNDS) database provides information on medical consumption (number and type of consultations, medications, transportation, etc.). However, this information is not linked to the pathology concerned. Similarly, the SNDS cannot be used to assess whether an individual has visited an ED more than once (again because of the lack of data linkage). Accordingly, primary care pathways cannot be directly analysed using data from this database.

In this context, we conducted a qualitative study using semi-structured interviews asking patients who had been hospitalized for COVID-19 about their experience in terms of their primary care pathway. Many evaluation methods use patients' experiences as an evaluation tool (e.g., tracer patient methodology) [4].

In addition to exploring the primary care pathway, it is important to identify significant events from the patient's perspective - particularly in terms of safety of the care provided - as well as patients' suggestions for possible areas for improvement [5].

The main objectives of this study were therefore to: i) identify and characterize the different types of primary care pathways in terms of duration, based on the experience of patients hospitalized for COVID-19; ii) identify patient-perceived significant events, safety of care dimensions, and areas for improvement.

METHODS

Population

Patients admitted to the Infectious and Tropical Disease Departments of the University Hospitals of Marseille (IHU) and Nice (CHU) for COVID-19 between September 2020 to December 2021 were eligible, irrespective of their mode of entry (e.g., transfer from the hospital ED or from another department in the hospital, or transfer from a day hospital) and mode of discharge (i.e., released from hospital after IHU/CHU stay, transfer from IHU/CHU to another department including ICU). Only patients and families of patients who gave their consent to participate were interviewed. This study is reported in accordance with the Standards for Reporting Qualitative Research. (**Appendix 1**)

The authors had no personal relationship with the participants.

Sampling method and sample size determination

Random sampling was performed by stratifying according to age group (under 50 years, between 50 and 70 years, over 70 years) and sex. Participants were interviewed until information saturation was reached (i.e., until the point where no new information emerged).

Data collection

The semi-structured interviews were conducted over the telephone or through videoconferencing by social science/psychology researchers and resident doctors in general medicine. No patient dropped out. Interviews were systematically recorded with the patients' agreement.

Interview guide and biographical approach

The interview guide (**Appendix 2**) was developed and iteratively revised during pretesting with five patients (data not shown). The interviews followed a biographical approach [6,7]. More specifically, they used a life-events calendar (**Figure 1**), which is a retrospective data collection tool highlighting the chronological order and proximity of events and important transitions in care pathways. This tool makes it possible to simultaneously analyse several aspects of a patient's life. The interview guide also addressed the patients' relationships with the medical profession, in particular with their general practitioner (GP), the latter's role in coordinating the COVID-19 primary care treatment process, the patient's perception of the seriousness of their health state during the acute phase, and their perception of the impact of the disease on daily life after release from hospital. Finally, patients were asked about areas they felt could be improved in the management of COVID-19, as well as the most significant events during their primary care for the disease.

Data analysis

The contents of the interview recordings were transcribed in full. All qualitative data collected during the interviews were entered directly into a database. Medical and hospital data were collected from each patient's file and/or from the IHU/CHU inpatient cohort database. Accordingly we had objective data for each patient.

From the patients' interview discourses, different socio-clinical characteristics (i.e., variables) were extracted which were coded and entered into an ad hoc sociodemographic and clinical data database (**Table1**).

Ethical and regulatory aspects

This study was approved by the French North West IV Ethics Committee (authorization N° EudraCT / ID-RCB: 2021-A01138-33 , 2 July 2021). The authors had no personal relationship with the participants. All the patients contacted received an information letter and a non-opposition form in accordance with this ethics committee's guidelines.

RESULTS

Socio-demographic profile of study sample

Data were collected on 31 patients, 16 of whom were male. Average age was 58.5 ± 16.4 years (28-87 years). Most patients (21) were living with a partner and had support from loved ones (**Table 2**).

Three categories of care pathways

The average primary care pathway duration (i.e., between symptom onset and the day of hospitalization) was 7.12 ± 4.3 days (0-16 days). From these pre-hospital timeframes we identified three types of pathways as follows: short pathways, which were less than or equal to 3 days; intermediate pathways, which were 3-10 days long; and long pathways, which were lasted more than 10 days. Patients were hospitalized for a mean of 7.55 days (± 5.8), and nearly one-third (n=9) were transferred to an ICU after being hospitalized in the IHU/CHU departments. Over half the patients had COVID-19 sequelae (n=16) at the time of the study interview (3-12 months after diagnosis).

Below, we will first present the similarities between the three different primary care pathways (i.e., clinical history, role of screening, recourse to primary care leading to diagnostic delay, and the key role of family and friends in the decision to be hospitalized. We will then describe the specificities of each pathway.

Similarities in pre-hospital pathways.

Clinical history: increasing severity of non-specific symptoms

Clinical history was similar for all 31 patients, beginning with the onset of intense and unusual fatigue often associated with cough or flu symptoms. Over the next few days, most patients described a deterioration of symptoms; specifically, asthenia became disabling and coughing increased, interfering with eating. As the disease progressed, the impact of the symptoms continued to intensify and patients' ability to move about, eat, and seek medical attention became increasingly difficult.

NK 239: *“Every day I felt more fragile. I wasn't eating anything...; I started to have more and more headaches, I started to cough, I couldn't stand up, I vomited... I had everything, the whole thing. Vomiting, diarrhoea, fever, headaches, aches, and pains... everything. By Sunday, I was already knocked out, dead.”*

In addition, nine patients spoke of a state of confusion (including cases of fainting) which impaired their ability to assess their overall condition.

The challenge of the screening test

Screening positive for COVID-19 was the gateway to receiving primary care which may or may not have subsequently led to hospitalization. Physicians and patients ruled out COVID-19 when a test returned negative.

This process was very detrimental for patients who could not access testing, for those whose results were delayed, and for those who had a false-negative result. Of the 31 patients interviewed, 9 reported that their COVID-19 symptoms deteriorated from one day to the next (cf. life-events calendar above) and at least one negative test (prior to a positive one). False-negative tests were often associated with chaotic pre-hospital pathways. One patient had had 4 tests which tested negative (probably all false-negatives) despite having symptoms before finally testing positive.

Patients described primary care as not effective.

A majority (n=28) of respondents felt GP were an important primary care resource for COVID-19, with only three respondents declaring the contrary.

Most patients (n=21) had consulted a GP after testing positive: 16 patients had a physical examination and 5 had a video consultation, while 8 patients had consulted in a hospital ED and were immediately discharged (the physicians there providing a negative diagnosis).

In total, patients had used the primary care system an average of 1.7 times during their primary care pathway. Only 4 patients were hospitalized without first consulting a doctor: two lived in a nursing home and were brought to hospital by staff ~~admitted directly to the hospital~~, one suffered from severe comorbidities which led his family to call an ambulance, and the last patient was a self-medicating physician.

In most cases, the participant's GP had prescribed and/or performed the COVID-19 test which resulted positive. GP had reminded patients of the guidelines for self-isolation ref and the procedure to follow in case of a deterioration of symptoms (i.e., calling the Emergency Medical Services, or consulting in a hospital ED).

Among the 27 who had seen a doctor (GP or ED physician), 7 felt that that the doctor did not adequately consider the severity of symptoms.

A 35-year-old patient with no comorbidities visited the same medical centre three times before hospitalization. He described feeling misunderstood and even angry about the primary care he received.

C8: *"I told them that I wasn't at all well, and they told me no, it's nothing, it will pass, it's normal"; Frankly, he relied on his... on his stethoscope 'breathing is fine, saturation is fine,*

so there's no worries, that's all, the fever is normal, it's part of the symptoms of COVID.... In a few days it will be fine, in 2-3 days it will go away'... But in the end, it didn't go away... On the contrary, it got worse.;... They are given instructions, they apply them, they rely on their results, but not on what the patients say. "

One patient who called her GP felt that he never took her seriously.

NK 239: *"I called my doctor again. I told him 'Doctor, I'm going to die, if this goes on I'm going to die'. He told me 'It's normal, COVID does this, you're fragile, and you have fragile health, it's normal to have all this'."*

Finally, her husband took the initiative to bring her to an ED.

Only five of the 31 patients had received treatment other than paracetamol. Two of these self-medicated. One was a GP, while the other used his asthma treatment (corticosteroids). The other three were prescribed antibiotics.

Patient denial of the severity of their condition

A majority of patients were unaware of the severity of their illness. They explained that this was because of extreme fatigue which put them in a state of confusion. The miscomprehension of their true condition could also be explained by the negative test results and/or mistaken reassurance from inaccurate GP medical consultations.

R5: *"I didn't answer the phone because I was tired.... You don't even think about saying I'm sick, you just think, that's it, I must just think about breathing, I have to think about breathing.*

One participant, a 28-year-old nursing patient who tested positive, self-isolated at home for six days without seeing her GP, despite her general condition progressively deteriorating.

The decisive role of loved ones

Loved ones played a very important role especially given the asthenia patients experienced. They intervened in care when they saw the patient's health deteriorating and his/her inability to act. Specifically, loved ones were often the 'trigger' person to decide that the patient had to be hospitalized. Thirteen participants were hospitalized by loved ones either directly (i.e., they took the patient to a hospital ED or called the emergency services) or indirectly (insisted that the patient's GP take action).

Specificities of the different types of primary care pathways:

Short care pathways

In many cases, short care pathways corresponded either to at-risk patients monitored by their GP or to patients who quickly tested positive and whose condition deteriorated rapidly after the symptom onset.

One participant, a retired patient who breathing by tracheotomy, had a positive PCR shortly after his wife tested positive. His condition deteriorated very rapidly; in less than 24 hours he went into respiratory failure. His wife called an ambulance which took him to the ED where he was examined before being sent home. Two days later, the episode was repeated, this time the patient being admitted the IHU. He remained there for two months.

Intermediate care pathways

A slight majority (51.6%, n=16) of the participants had an intermediate care pathway. This group was more heterogeneous than the other two groups.

Most of these patients experienced a deterioration of their general health condition around day 7 after symptom onset. Patients in this group who were hospitalized on or close to the fourth day after symptom onset, knew they were contact cases and tested quickly after symptom onset.

A typical case of a participant with an intermediate care pathway was a man in his seventies who lived with his wife. His first symptoms were fatigue, headache, and fever. He had been infected at a social event with friends. He did an antigen test on day 4, which was negative. His condition gradually worsened, and he consulted his GP a week after symptom onset. His doctor reassured him that his difficult breathing was not due to COVID-19, as the test on day 4 had ruled it out. He did not have a fever. The patient did not remember the doctor measuring his oxygen saturation or recommending any monitoring measures. That same evening, faced with deteriorating dyspnoea, his wife took him to the ED where he was diagnosed with COVID-19 complicated by a pulmonary embolism (Table 4).

Long care pathways

Young patients (i.e., < 50 years) were more likely to have long care pathways. They had often visited their GP and an ED several times and were - in their view - not taken seriously. Patients with a long care pathway were more likely to have been admitted to an ICU after a stay in IHU/CHU for COVID-19, and to present severe symptoms. Long care pathways were

characterized by more patients who had false-negative tests, leading to a mistaken belief that they did not have the disease.

One example is a 49-year-old woman suffering from high blood pressure and overweight. She lived alone and was not registered with a GP. Her first symptom was asthenia. She tried to visit a GP without success and ended up going to the ED four days after symptom onset. She was sent home, as her PCR test was negative and her clinical examination was normal. Over the next few days, her general condition deteriorated; several antigen tests all tested negative. She became increasingly tired; she said that she got "used to her condition" and did not try to look after herself anymore. She was found unconscious on the floor by a co-worker who went to her home out of concern that she was not answering her phone.

R5: *"I feel like I've aged 10 years! All my gestures are complicated; when I say my gestures, I mean climbing stairs, walking, doing sport, everything is complicated.... I felt extreme tiredness to do even the slightest action or make the smallest decision."*

One patient described a chaotic primary care pathway. He was a 35-year-old man with no comorbidities and in good general condition. Two days after symptom onset, he performed an antigen test and a PCR test, both of which were negative, and visited a medical centre as his GP was himself hospitalized for COVID-19. Given the negativity of the tests, the doctors ruled out a diagnosis of COVID-19.

C8: *"So they told me it was probably a flu, something, like a viral thing, so.... They didn't give me any antibiotics, so I went home."*

His general condition deteriorated thereafter, and he developed new symptoms including abdominal pain and diarrhoea. He visited the same medical centre for a second consultation. The doctors diagnosed gastroenteritis. Five days after the first symptoms, he had a third test, which was positive. A few days later, he went to the same medical centre for a third time.

C8: *"They knew it was for COVID, they gave me Well, they told me there was nothing to do, that I had to take paracetamol, and that's about it..."*

Finally, the next day, his wife decided to call an ambulance. He was transported to the ED where he was admitted to the CHU department after the results of an arterial blood gas analysis.

DISCUSSION

Main results

This qualitative study which employed an original life-events calendar approach explored patients' experience of primary care (i.e., pre-hospitalisation) pathways for COVID-19. Three types of pathways emerged from the participants' discourses. The first was short care pathways (i.e., ≤ 3 days between symptom onset and hospitalization), which concerned mainly elderly and comorbid patients followed closely by their GP after rapid symptom onset and progression. GP were often the actor who decided these patients needed to go to hospital. The second was intermediate pathways (i.e., 3-10 days), which represented just over half of the sample; these pathways did not have any specificity. Symptom severity was progressive not rapid, and initial screening often provided false-negative results. The third type was long care pathways (> 10 days), which generally concerned young patients with no comorbidity, most of whom had false-negative test results. These patients consulted GP more frequently and reported that physicians, especially those in ED, inaccurately diagnosed them as being COVID-19 negative, thereby creating a mistaken sense of reassurance. For these patients, loved ones played a key role in the primary care process and helped them recognize the severity of their condition.

One of the striking results of our study is the diagnostic delay observed in the long care pathways. A diagnostic delay is understood here as the relatively long period of time before a patient receives an accurate diagnosis and/or inadequate care given the severity of the symptoms experienced. This may be due to the patient's delay in seeking treatment or to problems in the healthcare system or a combination of these dimensions. Furthermore, at the height of the pandemic, the clinical context was characterized by prognostic and sometimes diagnostic uncertainty.

Strengths and limitations

This study has several strengths. First, to our knowledge, no publication to date has explored the primary care (i.e., pre-hospitalisation) pathways of patients with COVID-19. This is most likely because of the difficulty in collecting this type of data. Second, we used a biographical approach. The comprehensive chronological data collected using the life-events calendar helped us to get a clearer picture of the sequence of events before hospitalization. Third, the study sample profile was very heterogeneous. Fourth, the semi-structured interviews gave patients the opportunity to talk spontaneously about their care pathway, their experience of the disease, their relationship with care providers, and the key events in their pathway. It also

permitted them to make suggestions about how primary care could be improved for the management of COVID-19.

The study also has limitations. The primary one is the possibility of memory bias. Patients were interviewed sometimes up to a year after hospitalisation. Indeed, some participants had difficulty clearly remembering the sequence of events not only because of the amount of time that had passed since their illness, but also because of the tremendous fatigue it brought on. Moreover, the psychological impact of COVID-19 - sometimes involving admission to an ICU - had an impact on participants' memories and their interpretation of the sequence of events. However, some participants recalled their experience very clearly because of its life-changing nature. In addition, memory bias was limited thanks to the use of the life-events calendar, where events were detailed on a day-to-day basis.

Comparison with existing literature

Most published studies on primary care management are reviews of the clinical recommendation literature [8,9,10,11,12], and in general, most of the literature focuses on hospital management of COVID-19 [13,14,15,16,17,18]. Furthermore, no publication to date has investigated the implementation of primary care practice guidelines for the management of COVID-19 patients. The first French recommendations in April 2020 advised patients with mild symptoms to stay at home. Subsequently updated several times, guidelines quickly shifted their focus to emphasize the importance of remote monitoring with saturation measurement and home visits by nurses. In our study, only two of the 31 participants declared that their GP advised them to buy an oximeter and provided them with monitoring instructions. There is some literature on the implementation of teleconsultation in the management of COVID-19 positive patients [19,20,21,22]. One such study in Saudi Arabia showed the positive impact of video consultation-based follow-up [20]. In Germany, a primary care monitoring protocol called COVIDCare in Germany is currently under evaluation. The results of COVIDCare could be used to improve the management of the ongoing COVID-19 pandemic [23].

Perspectives

In the context of COVID-19 in France, GP are faced with the challenge of managing a high prevalence, low lethality disease (0.5%) with an uncertain prognosis (hospitalization rate 14.8%) [24]. They are confronted daily with pauci-symptomatic patients, few of whom see

rapidly progression to a severe state. The challenge of primary care surveillance is to identify patients at risk of severe COVID-19.

Management protocols to evaluate the syndromic presentation of COVID-19 are still urgently needed, including an initial assessment of risk factors and symptoms in order to evaluate the need for follow-up at home, follow-up consultations, and hospitalization. Continuous remote monitoring protocols are also needed for those at risk, and those presenting new signs of severe disease. Moreover, physicians should take into account the presence of patients' loved ones, a key influential group in the care pathway.

Based on the scientific literature, the patients' experiences and suggestions, we propose the following areas for improvement in the management and follow-up of patients with COVID-19:

Diagnostic strategy for testing

During a pandemic with a large influx of patients, it may be more efficient for a GP to rely on a negative test despite symptoms (test and treat strategy). We point out however that the usefulness of tests with poor sensitivity at high economic and social cost is still debated [25,26,27]. as they are sometimes counterproductive, and false-negatives can mistakenly reassure the GP, as observed in our study.

In this context, we suggest that:

- COVID-19-like symptoms be considered the result of COVID-19 infection until proven otherwise [28].
- systematic PCD on day 3 post-symptom onset be implemented after a negative antigenic test.

Follow-up strategy

The follow-up protocol below, based on patient experience could be beneficial:

- use 'safety-netting'^{*}[29] (i.e., information is given to a patient (or a family care giver) during a primary care consultation about actions to take if their condition should fail to improve or should deteriorate, and actions to take if they have further concerns about their health in the future. Safety-netting is a way to help GP optimize communication with patients to facilitate the latter's self-management in terms of health care and follow-up when a diagnosis or prognosis is uncertain.
- involve family and friends in follow-up.

- generalize follow-up consultations
- implement remote monitoring (telemedicine, home visits by nurses)
- use oximeter-based follow-up [30]
- screen for thrombotic risk factors

CONCLUSION

No etiological treatment for COVID-19 was available during the first two years of the pandemic (i.e., this study period). Such a treatment has recently become available [30, 31]. Despite this novel treatment, the importance of the role of coordination of the care pathway and monitoring by GP is no less diminished in the context of COVID-19 [30, 32]. GP have an even more important role to play during epidemic waves, when hospital services are put under severe pressure. Prospective studies in an unselected population presenting in primary care or hospital outpatient settings which examine combinations of signs and symptoms to evaluate the syndromic presentation of COVID-19, are still urgently needed. Results from such studies could inform subsequent management decisions.

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