Understanding and Being Understood: Information and Care Needs of 2113 Patients With Confirmed or Suspected COVID-19

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Abstract

To become a proactive and informed partner in postacute coronavirus disease 2019 (COVID-19) management, patients need to have the knowledge, skills, and confidence to self-manage COVID-19-related health challenges. Due to several restrictions and consequently social isolation, online platforms and forums where people can share information and experiences became more popular and influential. Therefore, this study aimed to identify perceived information needs and care needs of members of 2 Facebook groups for patients with COVID-19 and persistent complaints in the Netherlands and Belgium and patients with COVID-19 who registered at a website of the Lung Foundation Netherlands. Besides demographics and clinical characteristics, the degree of satisfaction with care during and after the infection as well as satisfaction with available information were assessed. Open text fields revealed specific information needs which were summarized. Patients with confirmed or suspected COVID-19 perceive various unmet needs varying from specific information needs (eg, information about permanent lung damage) to general needs (eg, being heard and understood). These data lead to several recommendations to improve care for patients with COVID-19 and justify further development of online platforms specifically addressing these unmet needs.

Keywords

COVID-19, corona, unmet needs, information needs, long-term symptoms, social support

Introduction

By the end of 2019, the World Health Organization was informed of cases of pneumonia of unknown etiology which turned out to be coronavirus disease 2019 (COVID-19) (1). Till now, COVID-19 has been confirmed in millions of people around the world (2). Furthermore, due to limited testing

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capacity, a clinical status which was considered not severe enough to be tested or to be hospitalized, or symptoms unknown at the time, there were many cases with suspected COVID-19. The majority of these patients was treated at home and symptoms were managed expectantly. Remarkably, part of these patients suffer from persistent symptoms (3) and report an impaired quality of life (4) emphasizing the complexity and severity of post-COVID-19 symptom burden.

A qualitative study revealed that COVID-19 patients are worried about an incomplete recovery of their health (5). This may, at least in part, be due to the fact that patient's knowledge about COVID-19 and the subsequent recovery process is limited. Indeed, to become a proactive and informed partner in post-COVID-19 management, patients need to have the knowledge, skills, and confidence to self-manage COVID-19-related health challenges (6). Due to several restrictions (eg, no large events and meetings, people were encouraged to work from home, many public places were closed, etc) and consequently social isolation, online platforms and forums where people can share information and experiences became more popular and influential. Especially during public health crises, like the COVID-19 pandemic, risk perception is elevated and patients rely even more on information from social media (7,8). Therefore, this study aimed to identify perceived information needs and care needs of patients with COVID-19 and persistent complaints who are members of online support groups.

Methods

Members from 2 Facebook groups for coronavirus patients with persistent complaints in the Netherlands ($\sim$11 000 members; "Corona ervaringen en langdurige klachten!") (9) and Flanders (Belgium, $\sim$1200 members; "Corona patiënten met langdurige klachten [Vlaanderen]") (10) as well as $\sim$1200 people who registered at a website of the Lung Foundation Netherlands (www.coronalongplein.nl), a platform for patients with respiratory complaints after COVID-19, were invited to complete an online survey between June 4 and June 11, 2020.

Demographics, marital status, educational level, smoking status, and self-reported pre-existing comorbidities were assessed. Furthermore, the survey contained questions about

- hospitalization at the time of the infection,
- confirmation of COVID-19 diagnosis for the nonhospitalized patients by physician based on computed tomography scanning/reverse transcription polymerase chain reaction,
- confirmation of COVID-19 diagnosis for the nonhospitalized patients by physician based on symptoms, and
- no confirmed diagnosis.

Symptoms during the onset of infection as well as during follow-up were assessed. Patients were asked if they were

worried about an incomplete recovery following the infection. Experience of support from family members, friends, employer, and colleagues for the current situation was rated by patients as follows: not applicable, rarely or never, occasionally, regularly, or very often.

Data are presented as mean and standard deviation or frequencies and proportions, as appropriate.

Care Needs

Satisfaction with care during and after the infection (aftercare) were rated: I did not need any care, very satisfied, satisfied, dissatisfied, or very dissatisfied. Patients who were very dissatisfied could choose the following reasons: I did not receive any care, I did not feel heard, my concerns have not been taken seriously, I could not consult my general practitioner (GP), or I could not consult a medical specialist.

Information Needs

Respondents were asked to indicate their satisfaction with the information available about COVID-19: no need for information about COVID-19, very satisfied, satisfied, dissatisfied, and very dissatisfied. Patients who were satisfied, dissatisfied, or very dissatisfied had the opportunity to enter further specific information needs in an open-text field. Answers were summarized with 1 or 2 words finally leading to 11 general topics:

1. future (future prospects, permanent lung damage, aftermath),
2. clarity (clear, coherent information),
3. aftercare ([support during] recovery),
4. "mild" COVID-19 ((course of) "mild" COVID-19 without hospitalization),
5. support (recognition, understanding, social support, contact with fellow sufferers),
6. follow-up (feedback/follow-up by GP/medical specialist, medical expertise),
7. testing (testing, certainty, immunity),
8. tips (advices, exercises, tips to exercise at home, recovery support),
9. research (future research, new insights, knowledge development),
10. unknown (much still remains unclear), and
11. other.

Coding of 100 answers has been randomly checked by JMD and RM (50 each). Disagreement (<5%) has been discussed until consensus was reached. Informative, appropriate quotes from the open-text fields were manually selected for each group to further illustrate patients' needs.

A word cloud has been created by automatically translating Dutch answers into English (via deepl.com) and pasting the translated text into a word cloud generator (tagcrowd.com) to visualize answers and demonstrate the variety of information needs. For creating the word cloud, 75 words have been

Table 1. Patient Characteristics.

	n = 2113
Women, n (%)	1803 (85.3)
Age, years	46.2 (11.0)
Marital status, n (%)	
Alone	446 (21.1)
Married/living together	1491 (70.6)
Divorced	149 (7.1)
Widow(er)	27 (1.3)
Level of education, n (%)	
Low	63 (3.0)
Medium	844 (39.9)
High	1182 (55.9)
Not specified	24 (1.1)
Smoking status, n (%)	
Currently smokes	131 (6.2)
Smoked before COVID, now quit	251 (11.9)
Never smoked	1731 (81.9)
BMI, kg/m^2	26.3 (5.2)
Self-reported pre-existing comorbidities, n (%)	
None	1239 (61.2)
1 comorbidity	541 (25.6)
≥2 comorbidities	279 (13.2)
COVID-19 diagnosis, n (%)	
Hospitalized	112 (5.3)
Nonhospitalized, confirmed based on CT/RT-PCR	345 (16.3)
Nonhospitalized, confirmed based on symptoms	882 (41.7)
Nonhospitalized, not confirmed by physician	74 (36.6)
Symptoms, n (%)	
Time since onset of symptoms (days)	79.3 (17.2)
Symptoms during the infection, n	14.1 (4.8)
Symptoms at this moment, n	7.0 (3.9)
Self-reported health status before the onset of symptoms, n (%)	
Good	1799 (85.1)
Moderate	301 (14.2)
Poor	13 (0.6)
Worried about incomplete recovery, n (%)	1027 (48.6)

Abbreviations: CT, computed tomography; COVID-19, coronavirus disease 2019; RT-PCR, reverse transcription polymerase chain reaction

selected automatically and irrelevant, or obvious words have been deleted manually (eg, "etc," "lot," "information," "info," "corona").

Results

Characteristics

In total, 2159 people responded to the online questionnaire (estimated response rate: 16%). Patients who were admitted to the intensive care unit (n = 15) were excluded. Additionally 31 respondents were removed due to missing data (n = 9), an onset of symptoms before January 1, 2020 (n = 8) or reporting that the onset of symptoms was less than 3 weeks ago (n = 14), resulting in 2113 patients (85% women, mean age: 46 ± 11 years, mean body mass index: 26.3 ± 5.2 kg/m^2) for the current analysis. More than half of the patients were highly educated, the majority had never smoked and

Table 2. Perceived Support From Family, Friends, Employer, and Colleagues by Patients.[a]

	Family	Friends	Employer	Colleagues
Not applicable	25 (1.2)	36 (1.7)	453 (21.4)	456 (21.6)
Rarely or never	86 (4.1)	156 (7.4)	232 (11.0)	211 (10.0)
Occasionally	399 (18.9)	633 (30.0)	389 (18.4)	483 (22.9)
Regularly	743 (35.2)	831 (39.3)	649 (30.7)	620 (29.3)
Very often	860 (40.7)	457 (21.6)	390 (18.5)	343 (16.2)

[a]Numbers present frequencies and proportions, n (%)

reported a good health status before the infection while two-third had no pre-existing comorbidity. More than one-third of the patients were neither hospitalized nor had a confirmed diagnosis. On average, the survey was completed 79 ± 17 days after the onset of the infection-related symptoms (Table 1).

The majority of patients perceived social support from family and/or friends regularly to very often. Around 23% and 37% of the patients did not or occasionally experience support from their family members or friends, respectively (Table 2).

Care and Information Needs

Approximately one-third of the patients were satisfied with care during and/or after the infection (Figure 1A and B). Around 20% of the patients were very dissatisfied because they did not receive any aftercare (Figure 1B) which was supported by the need for more information about aftercare (e-Figure 1, online supplement).

Around 37% of the patients were satisfied or very satisfied with the information available about COVID-19 (Figure 2). Patient needs were very heterogeneous and varied from specific information needs (eg, information about permanent lung damage) to general needs (eg, being heard and understood; Figure 3; e-Figure 1, online supplement).

Future. Almost half of the patients were worried about incomplete recovery (Table 1). Indeed, patients often wondered "how to proceed" or if and when they could go outside because they still experienced symptoms. Patients would also like more information about long-term complaints and duration of current persistent symptoms.

Clarity. Most patients indicated a need for timely, clear and reliable information: for instance, "according to several websites, patients with "mild" symptoms recover within 2 weeks which was not the case and therefore very frustrating." According to patients, information on the websites from the national and regional institutes was often contradicting and not up to date: "I would also appreciate better communication from the national institute regarding the recovery period of mild corona and an update of the list of symptoms."
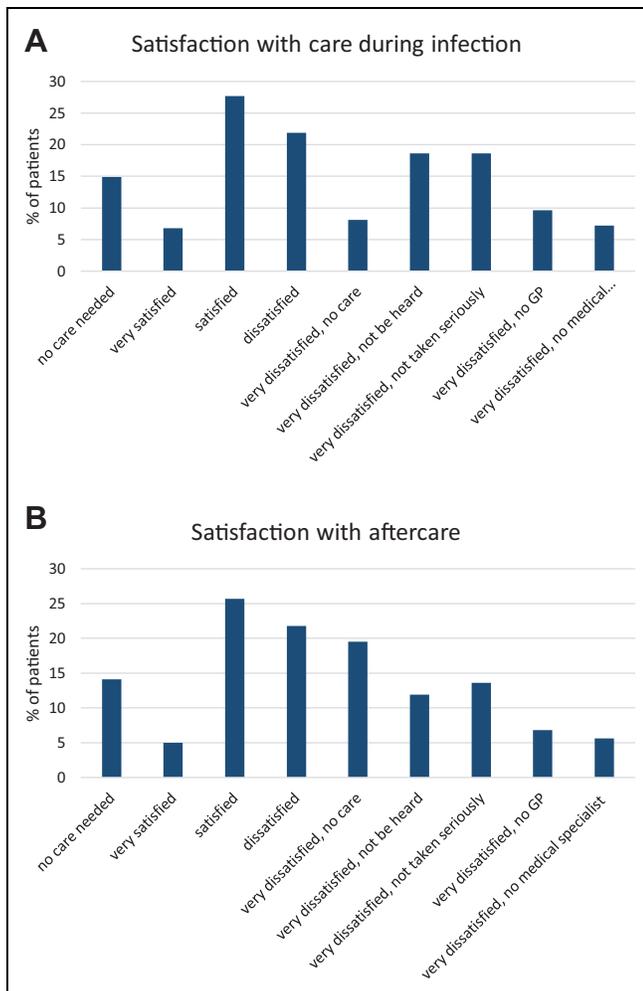
Figure 1. Satisfaction with (A) care during infection and (B) aftercare. GP indicates general practitioner.
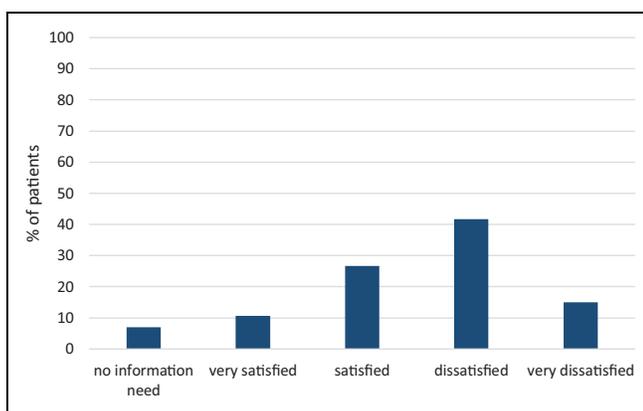

Figure 2. Satisfaction with available information.

Patients would further appreciate "updates from one reliable source," even if the answer is "we don't know."

Aftercare. Patients indicated information needs about aftercare and possible treatment options. They wonder how they can receive any aftercare without being hospitalized or have been seen by any physician, and if they get any aftercare (eg, rehabilitation), if there is "reimbursement for rehabilitation, also for patients who recovered at home." Additionally, according to patients, health care providers could be more proactive in giving information about rehabilitation.

"Mild" COVID-19. Patients indicated that they need information about the course and recovery of long-term "mild" symptoms without being hospitalized: "the news is mainly about the severe cases; information about 'mild' COVID-19 with persisting symptoms is limited." Another patient wrote that "it's labeled as 'mild' disease, but it feels very severe".

Support. Patients do not feel understood and not being taken seriously. "I would like to see more recognition for those of us who were not hospitalized"; "In the end, you already believe that it's just all in your mind." Patients indicated that they were looking for peers, "people who also go through this," to exchange and evaluate their experiences and to verify their symptoms.

Follow-up. Patients perceive that exchanging information and collaboration between professionals with different professions can be improved. They would further appreciate "a GP who monitors how things are going and thinks along with the complaints, thinks along with me about which support I might need and provides advice."

Testing. Patients indicated that they wanted a test to confirm their diagnosis (in the acute phase) or certainty that they have had COVID-19. "Without a test, it's all in your mind, it's a psychological thing." They were also wondering if they are still contagious since they still have clinical symptoms.

Tips. Patients were looking for some tips or tools to support or accelerate their recovery at home, "a practical guide" about what they could or should do (or leave) to improve their health. They would further appreciate "tips about how to cope with the situation (e.g. fatigue, acceptance)."

Research. Patients also see the need for scientific research since there is still a lot unknown; not only research about COVID-19 affecting the lungs but the whole spectrum of consequences of the disease. They are grateful for the current initiative.

Unknown. Although various unmet information needs exist, patients also realized that COVID-19 is a new disease and therefore a lot is still unknown; "there is simply no information yet."

Discussion

The current study is the first revealing various patient needs ranging from general care needs to specific information

Figure 3. Word cloud demonstrating various information needs. The bigger and bolder the word appears, the more often it is mentioned by patients.

needs in a large sample of patients with confirmed or suspected COVID-19 3 months after the onset of symptoms.

Care Needs

Abrams and colleagues recently stated that "the pandemic has created both challenges and opportunities for delivering care, as system adaptations influence the physician-patient relationship" (8, p. 2474). The current study showed that less than one-third of the patients were satisfied with the care they received during and/or after the onset of symptoms. Two-third of the patients were treated by a GP while 17% were treated by a medical specialist during/after the onset of symptoms (3). Common patient needs were related to aftercare, rehabilitation, tips and advices for exercises, and recovery at home. Indeed, only 20% of the patients were treated by a physiotherapist during/after the onset of symptoms while only 1.5% were treated by an occupational therapist (3). Patients were wondering whether they are eligible for rehabilitation or whether they are reimbursed for rehabilitation since the majority have not been hospitalized or treated by a medical specialist. Following on from this, the Global Rehabilitation Alliance "urges decision makers to ensure that rehabilitation services will be available for all patients with COVID-19 in the acute, post-acute and long-term phase" (11), which is echoed by an European Respiratory Society and American Thoracic Society-coordinated International Task Force (12). Additionally, a considerable proportion of nonhospitalized patients with COVID-19 depend on others for personal care underlining the need for optimal treatment strategies to restore patients' independency (13).

Rating and understanding patients' satisfaction and interpreting their feedback (cocreation) provide important insights and outcomes to ultimately improve health care services (14). A considerable proportion of patients who were very dissatisfied with their care during the infection reported that they did not feel heard or taken seriously while dissatisfaction about aftercare was mostly explained by receiving no care. Indeed, patients also indicated that providers can play a more proactive role and be more concerned or involved in the patient journey. Patients are challenged as active and essential members of the treatment team (15), but health care professionals are also encouraged to be involved, listen, and understand (16). Patient experience has been associated with perceptions of care embracing the aphorism that "patients don't care how much you know until they know how much you care" further underlining the importance of relational aspects of care and communication skills (17,18). However, the absence of face-to-face conversations, fear of infection, and/or personal protective equipment may hinder communication and challenges (virtual) shared decision-making (8). Therefore, health care professionals are encouraged to engage patients in their own home, create opportunities for patients to access multiple platforms, and/or provide access to care team members through telehealth (8,19).

Information Needs

Meeting information needs has been shown to be associated with patients' satisfaction with care and quality of life (20). In the current study, besides patients who were dissatisfied or very dissatisfied, also patients who were satisfied with the available information indicated relevant unmet information needs. Patients specified the need for "clear information" or "clarity" since they often perceived contradicting information and did not find information about their specific situation: persistent, "mild" symptoms without being hospitalized. Till now, patients with severe COVID-19 who have been admitted to the hospital received most attention

from researchers and society. A social media listening study revealed important unfiltered and uninfluenced insights on the impact of disease on patients' life: patients actively share experiences on forums and seek information on social media (21) further underlining the need to interconnect with patients where they are: online. Indeed, social media influence during COVID-19 has resulted in an "infodemic" highlighting the importance of patient engagement (8). Overall, patients tend to prefer the Internet for the ease of access to information, while they trust their physicians more for their clinical expertise and experience (22). Thus, timely and reliable information by physicians or other trusted parties (eg, patients' associations, like Lung Foundation Netherlands, for instance via www.coronalongplein.nl) may play an important role. Furthermore, providing information is essential for the shared decision-making process (23) and to empower patients to become active stakeholders by utilizing their knowledge, capabilities, and responsibility (15,24). In addition, in this context, considering the educational level of the target population is essential since it is associated with knowledge processing (25). Remarkably, the majority of the current study population was highly educated. In addition, patient's context and social facilitation influence self-management (26) emphasizing the need for holistic models considering patient's family and social context (27). Providing information and knowledge to the patient's social environment might contribute to the patient's degree of self-management. In the current study, 23% of the patients did not or occasionally experience support from their family members which might have stimulated their search for recognition online.

Although the number of research articles is rapidly increasing, there are still lots of unanswered questions with regard to COVID-19. Patients indicated the need for certainty and reported to be worried about incomplete recovery. Patients wanted clear information but also acknowledged that a lot is still unknown. On the one hand, timely testing might prevent a specific degree of worriedness and contribute to more certainty and understanding of the situation. However, scaling up testing capacity needs some time. On the other hand, in uncertain situations where evidence-based facts and knowledge are lacking, goal setting and dispositional hope might be included as components of any physician–patient shared decision-making approach (8).

Recommendations for Health Care Providers

Coronavirus disease 2019 has created many difficulties but has also forced us to re-examine how to provide more patient-centred and high-quality care (8). The current findings revealed some important insights leading to several recommendations to improve care for patients with (mild) COVID-19:

- Listen to the patient and try to understand what matters to them but also fulfill a proactive role and be involved in health care.
- Know patients' needs, adapt information, be prepared for future scenarios.
- Provide timely, clear and reliable information, preferably using a central online information point.
- Involve patients' context and environment, consider social support.
- If possible, timely facilitate testing for COVID-19 and follow-up of persistent complaints.
- Facilitate any aftercare, ranging from tips or advices about exercises at home to an (inpatient) rehabilitation program, if indicated: provide the right treatment to the right patient at the right time.
- Connect with patients where they are: online and preferably live.

Limitations

The external validity of the current findings is limited, as mostly women responded, who are more likely to present themselves with symptoms than men (28). Moreover, only COVID-19 patients from 2 Facebook groups with self-reported persistent symptoms and patients who registered on www.coronalongplein.nl were included in the study. The current study should mostly be used to create a broader awareness among health care professionals, employers, insurers, and society about the unmet information and care needs of patients with "mild" COVID-19 and persistent symptoms. The size of this persistent symptomatic group of "mild" COVID-19 remains to be determined, as well as their symptom trajectory over time. Taken the abovementioned limitations into consideration, the current study population might not present a reliable sample but it highlights the existence and relevant information and care needs of a large unheard group.

Conclusions

Patients with confirmed or suspected COVID-19 perceive various unmet information and care needs. These data justify further development of online platforms specifically addressing these unmet needs. Moreover, effort should be put into involving and educating family, friends, colleagues, employers, and other community members of these patients with persistent complaints.

Authors' Note

approval of this study by the committee was not required (METC2020-1978). All procedures in this study were conducted in accordance with the medical ethics committee of Hasselt University (MEC2020/041) and medical ethics committee of Maastricht University (METC2020-1978) approved protocols. All respondents gave digital informed consent.

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Supplemental Material

Supplemental material for this article is available online.

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