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Barriers and Facilitators for Patient-Centered Care for Hospitalized COVID Patients: Lived Experiences from Ex-hospitalized Patients and Health Care Professionals

Lieke van Disseldorp, Caro-Lynn Verbaan, and Annemarie Wagemakers

The COVID pandemic has challenged patient-centeredness, an increasingly valued approach in the pursuit of high-quality care. This research aimed to explore barriers and facilitators for patient-centered care (PCC) in the context of the COVID pandemic. Semi-structured interviews were conducted with seven ex-hospitalized COVID patients and ten health care professionals (HCPs) who have cared for this patient group. A phenomenological design was used with a photo-elicitation method to capture participants' lived experiences. Findings indicate that COVID entailed multiple and interrelated barriers across all dimensions of PCC. COVID care practices like intubation and isolation also negatively impacted patients' physical comfort, ability to communicate, and emotional well-being. Despite HCPs' motivation to improve patients' well-being, they were hampered by serious barriers, including a lack of time and challenges in care coordination. Due to these difficulties, the question can be raised whether PCC during a communicable disease pandemic is feasible. Nevertheless, as shown in this study, key facilitators such as digital communication tools and a holistic and personal care approach demonstrate that rendering PCC remains vital and should be aimed for and that this could be informed by the lived experiences of HCPs and patients.

Key words: COVID, patient-centered care, lived experiences, hospitalization, photo-elicitation

Introduction

On December 1st, 2021, the COVID pandemic reached 262 million reported cases, with more than 5.2 million associated deaths (WHO 2021). Those infected can experience mild symptoms like coughing, shortness of breath, and fever but can also suffer from serious complications like multiple organ failure and need to be hospitalized (Guo et al. 2020). Infections and hospitalization rates have been fluctuating since spring 2020, with consecutive peak periods (Ritchie et al. 2020). This has put a strain on the quality of care for hospitalized COVID patients, for example, due to staffing shortages and a lack of time for health care professionals (HCPs) to recover physically and mentally (Goudsmit 2020).

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The disease course of hospitalized COVID patients has been studied in-depth (Siordia 2020). However, less attention has been paid to the broader physical, mental, and emotional aspects of patients' well-being during hospitalization (Hu et al. 2020; Sun et al. 2021). The few studies focusing on mental health issues reported that hospitalized COVID patients experienced mental health disturbances like depression, anxiety, and insomnia (Hu et al. 2020), fear, and stress (Sun et al. 2021). The overall health of hospitalized COVID patients should, therefore, receive attention as well in order to reach a high quality of care.

In the pursuit of high-quality care, patient-centeredness has been increasingly recognized (Langberg, Dyhr, and Davidsen 2019) since it positively relates to patients' well-being and quality of life (Aarts et al. 2012; Ponte et al. 2003; Stewart et al. 2000; Vogel, Leonhart, and Helmes 2009). Patient- or person-centered care (PPC) is about providing care that is empathic, compassionate, and receptive to a patient's needs, preferences, and values, whereby patients are informed in decision making (Rathert, Wyrwich, and Boren 2012). Holism is a key feature of this approach since this corresponds to a focus on not only physical well-being but also emotional and spiritual health (Sidani and Fox 2014). In this research, we operationalized patient-centeredness

Table 1. Dimensions of Patient-Centredness

Patient-Centredness Dimension	Description Informed by the Institute of Medicine (2001)
Respect for patients' values, preferences, and expressed needs	Enabling patients to be informed and involved in decision making as they wish, attending to both their physical and emotional needs, and applying a customized approach and cultural competence.
Coordination and integration	Ensuring adequate and timely information reaches those who need it at the appropriate time, and realizing smooth transitions across settings (including hospital discharge).
Information, communication, and education	Clear communication of diagnosis, prognosis and treatment options, in a manner that an individual prefers and using understandable language. Important aspects in this dimension are the trustworthiness and responsiveness of information.
Physical comfort	This includes timely, tailored and adequate mitigation of pain, shortness of breath and other discomfort.
Emotional support – relieving fear and anxiety	Reducing emotional and spiritual suffering from anxiety due to uncertainty, fear of pain, disability, loneliness, or the (financial) impact on one's family.
Involvement of family and friends	Including family and friends in decision making and enabling them to support the patient, and tending to their own needs and making them feel comfortable in the healthcare setting.

according to the six dimensions endorsed by the Institute of Medicine (Table 1).

Previous research has shown positive relationships between PCC and patient well-being and satisfaction (Rathert, Wyrwich, and Boren 2012). This is important because (1) patients' satisfaction with the care process is an important outcome in itself (Rathert, Wyrwich, and Boren 2012), and (2) patient satisfaction is related to other variables, like self-management behavior and adherence to the treatment plan (Rathert, Wyrwich, and Boren 2012; Robinson et al. 2008). During the COVID pandemic and health system disruption, the need for PCC was felt instantly since COVID (care) complicated connection, engagement, communication, and touch, among other things (Sentell et al. 2021). However, little is known about the lived experiences of patients and HCPs regarding PCC for hospitalized COVID patients. The aim of this study was to explore barriers and facilitators to PCC so as to inform strategies to enhance patient well-being in times of a pandemic.

Research Methods and Data Analysis

We used a qualitative phenomenological study design, as this is specifically suitable for understanding emotional and intense experiences (Merriam 2009), such as hospitalization with COVID. Phenomenological research focuses on “the meaning for several individuals of their lived experiences of a concept or a phenomenon” (Creswell 2007:57).

To gain a complete understanding of the care for hospitalized COVID patients, we explored both patients' and HCPs' lived experiences. In line with phenomenology, we used semi-structured interviews with open questions to enable patients and HCPs to explicate what mattered most to them. To prevent predetermined questions and presuppositions from underexposing what mattered most to participants and to deepen understanding of their perspectives, data elicitation was centered around the perspective of participants themselves through a photo-elicitation method (Plunkett, Leipert, and Ray 2013). This method fits with the photography-based research tradition within anthropology (Glaw et al. 2017; Harper 2002). In addition, photovoice-related research has proven to be valuable in exploring PCC (e.g., Nizzer, Ryan, and McKay 2020) and HCPs' experiences during COVID (e.g., Badanta et al. 2021). The Social Sciences Ethics Committee from Wageningen University granted official approval for this research on November 11, 2020. This included approval for, amongst others, the recruitment strategy.

We used purposive sampling with convenience (snowball) sampling to recruit ex-hospitalized patients (“patients” from now on) and HCPs for the interviews, using the researchers' social network and the social media LinkedIn and Facebook, including a Facebook group for Dutch COVID patients with long-lasting complaints. Inclusion criteria were (1) being an ex-hospitalized COVID patient in a Dutch hospital (at a regular [COVID] ward or an ICU) or having cared for these patients; (2) being at least eighteen years old, and (3) speaking Dutch or English. In total, seven patients and ten HCPs were interviewed

Table 2. Patients' Characteristics

Patient	Age	Sex	Hospitalization Duration	Hospitalization Period	Admitted to ICU
1. Alicia	56	Female	7 days	September 30, 2020 – October 6, 2020	No
2. Lucy	56	Female	5 days	April 2020	No
3. Michelle	50	Female	5 days	October 16, 2020 – October 20, 2020	No
4. Charlotte	56	Female	5 days	April 10, 2020 – April 14, 2020	No
5. Olivia	58	Female	8 weeks	April 16, 2020 – June 11, 2020	Yes (1 month)
6. Francis	65	Female	5 days	May 1, 2020 – May 5, 2020	No
7. Mike	60	Male	Almost 6 weeks	August 8, 2020 – September 16, 2020	Yes (10 days)

(Tables 2 and 3). All HCPs were nurses, except for one who was a physiotherapist. After these interviews, no new themes emerged, as interviewees' stories showed only minor differences.

The interviews took place in November and December 2020. Prior to the interview, participants were asked to choose six images (self-taken or from sources such as the internet) about

Table 3. HCPs' Characteristics

Healthcare Professional	Age	Sex	Working Experience in a Hospital	Working Experience in Current Hospital	Original Ward(s) or Function	Ward(s) During COVID	Period of Caring for COVID Patients
1. Lisa	24	Female	2 ½ years	2 years	Cardiology	COVID ward	April 2020
2. Helen	56	Female	38 years	38 years	Nurse anaesthetist	ICU; operating theatre	Mar. – May 2020
3. Susan	27	Female	4 years	1.5 months	ICU	ICU	Mar. – Aug. 2020, Oct. 2020 – Mol*
4. Steven	57	Male	12 years	3 years	Internal and pulmonary medicine and oncology	COVID ward	Mar. – June 2020 Oct. 2020 – Mol*
5. David	28	Male	9 years	9 years	ICU	ICU	Mar. 2020 – Mol*
6. Daisy	25	Female	4 ¼ years	4 ¼ years	Pulmonary medicine	COVID ward (as coordinator); ICU; pulmonary medicine	Mar. 2020 – Mol*
7. Patricia	23	Female	1 ¼ years	5 months	Mixed nursing ward	COVID ward; Mixed nursing ward	Apr. 2020, Nov. 2020
8. Karen	60	Female	43 years	16 years	Urology	COVID ward; urology	Apr. – May 2020
9. Megan	35	Female	11 years	5 ½ months	Geriatric trauma physiotherapist	ICU	Mar. – July 2020 Sept. 2020 – Mol*
10. Melanie	24	Female	2 ¼ years	2 ¼ years	Internal medicine, geriatrics, and rheumatology	COVID ward; internal medicine, geriatrics, and rheumatology	Mar. 2020, Oct. 2020 – Mol*

* Mol = Moment of interview

something that showed or symbolized the barriers or facilitators in the care received or given and send these to the researchers. Informed consent was obtained for recording the interview and using the interview data, including the images collected by participants. We conducted the interviews via video calling ($n=14$) or phone ($n=3$) due to social distancing measures. During the interviews, patients were at home, and some indicated to still have physical complaints like shortness of breath or psychological complaints like emotional instability. The interviews lasted between twenty-two to eighty-two minutes ($m=48$). The interviews began with questions about participants' backgrounds: for patients about their hospitalization and for HCPs about their working experience and care for COVID patients. Next, we discussed the images through questions like: "What does the image show?", "What is the reason to choose this image?", and "What feelings does this image evoke?" Follow-up and probing questions were asked based on the interviewee's answers.

Participants were given pseudonyms to protect their privacy. Interview data were analyzed with ATLAS.ti software. First, codes were formulated based on the six dimensions of PCC. Next, within these main codes, inductive coding was used to stay close to the original data (Linneberg and Korsgaard 2019) and to identify the experienced barriers and facilitators in PCC. Subsequently, subcodes were clustered based on similarities and differences in meaning, and these were discussed and revised by all authors until a consensus was reached. Finally, the results were synthesized into a coherent analytical narrative and illustrated with quotes and images. The images from secondary sources that participants collected were checked for copyright, but no restrictions were found.

Findings

Participants' lived experiences reflected multiple barriers and facilitators for PCC. The findings are structured into paragraphs that each refer to one of the six dimensions of PCC.

Physical Comfort

Patients' physical comfort could be severely affected by the disease, as illustrated by a HCP:

The state that people were in like, normally someone would look well groomed, sportive, would be busy in the sun. Now they were lying in a bed like this, all, well, wasted away, their hair all wet of the sweat and the dirt, and intubated of course.... Then you think, "Wow, how ill a person can be. I hope it will turn out well." (HCP Helen)

Specific care practices negatively impacted physical comfort as well. These included intubation (although the administration of oxygen did relieve shortness of breath), side effects of medication, and care instruments like cannulas. In addition, patients' arms were sometimes fixed to their beds to prevent them from pulling their tubes and infusions out of restlessness when waking up from sedation. An alternative for this fixation was using gloves, but this could be extremely uncomfortable,

Figure 1. Wishing to Look Out the Window (Patient Olivia)



according to the experiences of one patient, Olivia, who was hospitalized for eight weeks and admitted to the ICU:

To be safe, they put mitts on [my hands], those were really tight. What I can remember, I was busy for hours and hours, like this, with my molars and teeth, to untie these mitts. ... And these mitts were so hot, oh, it was such an uncomfortable feeling. Such a fixating feeling, ... I wish that to no one. (patient Olivia)

COVID symptoms and treatment also affected patients' ability to absorb information and/or express themselves. Patient Olivia described that many things passed her by at the time of hospitalization as well as afterward:

I was aware that there was a window behind me. So actually, I really wanted the bed to be positioned the other way around, so I could look out the window! ... But like I said, I could not think clearly and talk, so I could not express that. (patient Olivia, Figure 1)

Offering patients physical comfort—and even basic care—was hampered by HCPs' lack of time, mainly due to staffing shortages. Patient Olivia illustrated this as follows:

In the ICU, they are there for you 24 hours [a day]. This is a different story in another ward. They don't have sufficient staff for so many patients. So, in the beginning I could not control my urge to go to the toilet. And then you start calling, but nobody comes! ... Before corona, I was just a healthy person, you know, and then suddenly you start defecating in your trousers! ... You are completely dependent on staff... [but] there is no staff! (patient Olivia)

Emotional Support—Relieving Fear and Anxiety

The emotional effects of being hospitalized with COVID seemed to differ between patients; two patients indicated that they were not significantly affected, whereas others talked about a traumatic experience or suffering from mood swings and nightmares (even after discharge)

Figure 2. Jar of Isolation (Patient Alicia)



and negative emotions like loneliness, fear, confrontation, and incomprehension.

One of the most prominent negative emotions was loneliness, which is strongly related to patients' isolation and feelings of being locked up, as reflected in the following patient images:

So that is the jar that I'm in, in my isolation, all alone... and you feel very small. You feel very small, very pathetic. ... It makes such an impression on you if you are there all by yourself. (patient Alicia, Figure 2)

This is a picture of a fence in a concentration camp. And that was the feeling I had sometimes in that room in the hospital, [with] those doors that were also kept closed so anxiously and you really feel locked up. (patient Francis, Figure 3)

Another important emotion was fear. Fear was induced by insecurity regarding one's prognosis and by suffering from the disease as well as from certain care practices, mostly related to sedation and ventilation. Both patients and HCPs indicated that waking up from sedation after a period that could be weeks could make patients seriously confused or even delirious, disoriented and agitated, and scared. Being intubated and surrounded by HCPs wearing full Personal Protective Equipment (PPE) formed additional stressors: patients described PPE as "surreal," "inhuman," and "confrontational with being contagious." Feelings of confrontation were also evoked, for example, by witnessing other COVID patients suffer or even

Figure 3. Fence of a Concentration Camp (Patient Francis)



die and by frightening stories in the news about the pandemic. These negative emotions were aggravated by the general lack of knowledge about the disease and appropriate treatment, as well as the incomprehension displayed by people in patients' social networks as well as by society in general:

And still, it can drive me crazy, even if I don't have energy, how mad it makes me feel when people react like, "Ah come on, it's just a little flu." (patient Alicia)

Finally, patients were afraid they would contaminate their loved ones or even never see their loved ones again.

HCPs offered emotional support by showing understanding and empathy for patients. For example, patients said that nurses comforted and encouraged them by telling them that things would be all right and by celebrating their progress in recovering. HCPs also used distraction and humor to lift patients' moods because of the heaviness of the situation.

Involvement of Family and Friends

All patients expressed the need for contact with loved ones, which was often impeded, however, by strict safety rules prohibiting physical patient visits, especially in the beginning of the outbreak. Although visitor policies varied between hospitals and over time, restrictions could also apply when a patient was admitted to the ICU, as explained by an HCP:

During the first wave, there was a patient at the pulmonary ward who passed away during my shift, and two family members were allowed to be there, two other kids were not, that was just not possible. And then we turned the bed towards the door, so that those family members could say goodbye from behind the door. (HCP Daisy)

Practical barriers like the transfer of patients to other hospitals existed as well, besides emotional barriers like patients' and visitors' fear of contamination and the emotional intensity of these visits and patients' resulting exhaustion. For example, a patient explained to prefer staying in touch with loved ones by phone because physical visits would have been too tiring and because she was afraid to start crying and make her visitors sad as well.

Patients stayed in touch with loved ones via calling, text messaging, or social media. Sometimes hospital tablets were offered to support patients with video calling. Video calling with family members was especially useful for reassuring confused patients who were waking up from sedation. Other strategies to connect patients with family and friends were calling while seeing each other through a window and putting pictures of a patient's family on the wall of the hospital room.

HCPs recognized the importance of patients' contact with family members for their recovery process and for mitigating feelings of loneliness and fear. At the same time, for family members, it could be quite disconcerting to witness the state patients were in. HCPs tried to update family members regularly about the patient's condition and the care process, but lack of time made it difficult to have extensive contact.

Respect for Patients' Values, Preferences, and Expressed Needs

The extent to which HCPs paid attention to patients' needs varied and depended on their background, according to HCPs' experiences with other HCPs. For example, an HCP explained that OR nurses are trained to pay attention to patients' emotions and explain to them what is happening, whereas in the ICU, the focus is more on the technical aspects of care:

That man was very short of breath, and everyone was more concerned with the machines around him than with that patient himself. . . . So I just took that man's hands. . . . I really felt like, "I just need to say something to that man, I won't just leave him alone. . . ." For us [at the OR], this is very normal, but I have the feeling that they are not so used to that in the ICU. That they are rather busy with the technical aspects, but, well, not so much with the patient at that moment. (HCP Helen)

Patients' stories indicate that they sometimes experienced a lack of empathy from HCPs, for instance, with regard to the strict visitor protocols:

Then my husband was dismissed rather harshly, "No you can't come in here!" . . . So that really was a shock, and I did not even have time to say goodbye to him, because these connecting doors vanished, and he could leave! (patient Francis)

HCPs also struggled with a lack of time and other challenges that complicated the provision of PCC. This was clearly demonstrated by one HCP, who revealed how the PPE negatively affected HCPs' patience:

Sometimes you really think about patients, "Come on, hurry up a bit so I can get some fresh air too." (HCP Lisa)

However, generally, HCPs did their best to provide disease-related care as well as personal care and to pay attention to patients' wishes like their preferred manner of toilet use but also having a single room with privacy, a tablet from the hospital, and a nice (window) view.

Patients valued HCPs' efforts to realize their wishes, even if this could not be achieved. Especially HCPs' openness to ideas and feedback from patients and their proactive attitude were valued:

But here, they really looked at the big picture so to speak. And that you didn't feel like a number, that was very pleasant actually. (patient Michelle)

However, attention for patients' needs after their hospitalization appeared to leave room for improvement:

The care in the hospital is very good, and everyone is very kind, but the moment you leave the hospital, you are no COVID patient anymore, or you are, but you have to do it on your own. And you have little guidance in that. (patient Michelle)

Patients who did receive aftercare were positive about the inclusion of psychological care, physiotherapy, the

Figure 4. PPE (HCP David)



provision of protein drinks, a survey from the hospital, and being visited by one's general practitioner. Besides, an HCP explained that she and her colleagues kept a diary for ICU patients so that they could read what had happened later on and share this with family members. Another HCP indicated that her hospital offered guided tours of the ICU for patients after hospital discharge, where patients would be informed about what happened during their hospital stay and in what room they were in. This was initiated to help patients cope with their experiences.

Information, Communication, and Education

Participants explained that communication was hindered due to COVID as well as its treatment and care. As described before, patients' inability to speak clearly and to absorb information, as well as the use of certain care instruments like cannulas and PPE worn by HCPs (Figure 4), could hinder their communication with HCPs. Moreover, PPE could even prevent patients from recognizing the HCP providing care to them:

I only saw eyes. Because everyone was completely wrapped up, like Martians. . . . They see me, but I do not see them. I do not see facial expression, I see nothing. (patient Alicia, Figure 5)

PPE turned out to be especially problematic for patients who were waking up from sedation:

Figure 5. "I See, I See, What You Don't See" (Literal Translation) / I Spy (Referral to a Game) (Patient Alicia)



Many patients are confused or delirious, and then some kind of a Martian is standing in front of you. Well, that does not really help for communication so to say. (HCP Susan)

Negative feelings about PPE were mitigated by HCPs' kindness and enabling patients to witness HCPs put on their PPE. On the other hand, from HCPs' perspective, PPE paradoxically also enabled close contact:

I have a suit on...so I am free to touch someone, I can put an arm around someone.... Once you had the suit on, ...you could really do more. ... The contact that had become impossible in daily life. And that was very special (HCP Karen)

Another HCP explained that she increasingly used her eyes to make contact:

People said, "... You know, at a certain moment you start to learn that, if you only see each other like this, [if you] are only cared for like this, then you can deduce very much from the eyes." (HCP Patricia)

Other measures that facilitated communication include having the same HCPs care for a certain patient, repeating introductions—while preventing patients from feeling foolish—and equipping PPE with HCPs' pictures and names—which was also helpful for HCPs' colleagues. One patient described the latter as follows:

I found that a golden opportunity...nursing staff who were in such a mummy suit, with a picture of themselves next to their name sign, so you know, "Oh, that face belongs to that person." (patient Francis)

Next to communication issues, other problems related to a lack of patient involvement in the care process. Besides, several patients missed information about their condition, symptoms, and (after)care plan during their hospital stay:

Sometimes I asked specific things, and then they didn't answer, and then I thought, "Well, I think they know more than they're saying, but they're just trying to keep you calm." ... But I think that, eventually, it would have made me calmer if I had known.... That gives a lot more clarity. (patient Michelle)

Communication and information provision were further impeded by HCPs' lack of time to talk with patients—which was, in turn, worsened by the need to wear PPE—and frequent staff changes, which made it difficult to build a connection with patients. In addition, due to staffing shortages, specialized HCPs were not always available to provide specific information.

Coordination and Integration of Care

Coordination of care appeared to be a challenge due to the high care demand, the strict protocols, the staffing shortages, and the required expertise and skills. Regarding the latter,

Figure 6. Sense of Togetherness (HCP Daisy)



the variety in HCPs' backgrounds led to large differences in knowledge and experience:

If you first have to explain every simple thing that you ask from someone, then it doesn't buy you time and actually only costs you energy. So then you can almost do it better yourself than let someone else do it. (HCP Susan)

These differences in knowledge and expertise also made it difficult to determine which tasks could be performed by which HCP, especially when HCPs did not know each other yet.

HCPs mentioned several possibilities to coordinate care more efficiently. One HCP was very positive about simulation trainings that were organized, which taught HCPs from different backgrounds to work together smoothly. Also, customization in the assignment of tasks appeared helpful, that is, assigning those with the most relevant knowledge to COVID wards and letting externals take over their regular and less complex work. As an example, one HCP mentioned stewardesses assisting HCPs in correctly donning and doffing their PPE and being dedicated to turning and mobilizing patients, so nurses had more time to provide care. Other facilitators for more efficient care coordination care included (1) appointing one general contact person or coordinator; (2) having experienced HCPs train their new colleagues; (3) implementing a buddy system with new colleagues assisting a supervising (ICU) nurse; (4) working with a color system, which clarifies one's background and tasks; and (5) organizing daily kick-off meetings and introduction rounds.

Finally, several HCPs indicated that having a permanent team composition was important for overcoming differences in background and unfamiliarity with one another. A permanent team facilitates a sense of togetherness and team spirit, which was highlighted as a significant factor stimulating collaboration during the outbreak:

It's so beautiful to see that from so many sides...so many people come and say, "I'm here to help, too!" ... That we just do all this together, even though we don't know each other, we say, "Good that you're here! We'll make it work today." Yes, that is very special, a sense of togetherness really dominates there. (HCP Daisy Figure 6)

Discussion

This study described barriers and facilitators for PCC for hospitalized COVID patients based on lived experiences, with the aim of informing strategies to enhance patient well-being in times of a pandemic. To our best knowledge, this is the first study focusing on COVID PCC from both patients' and HCPs' perspectives. Their stories show that this pandemic of a novel and communicable disease raised substantial barriers to each dimension of PCC. HCPs showed various (innovative) strategies to cope with these barriers, for example, providing information to and making contact with patients, but they were hampered by several factors like a lack of time and challenges in the coordination of care. Several aspects of COVID (care), such as intubation, fixation, PPE, and isolation, were found to threaten multiple patient-centeredness dimensions simultaneously. This implies that the barriers and facilitators identified should be considered with attention to their interrelations across the patient-centeredness dimensions.

However, it must be noted that not all barriers and facilitators reflected in interviewees' stories only pertain to the COVID pandemic. Whereas, for example, PPE and a lack of precise knowledge regarding contagiousness and disease outcomes are elements that separate COVID from many other hospital disease states, barriers to PCC like emergency of care and staffing shortages often play a role in the broader health care system as well. For example, Fenton et al. (2012) found that higher patient satisfaction was associated with lower emergency department utilization. However, these more general factors played an important role in COVID care, which makes their influence on patient-centered care relevant to this research.

A second note is that not all barriers and facilitators from the interviewees' narratives *directly* influence the patient-centeredness of given *care* itself. For instance, frightening stories about the pandemic in the news severely impacted a patient's emotional state, but this could be considered an external factor. However, since the anxious uncertainty typically characterizing the COVID pandemic did affect HCPs' ability to provide emotional support (one of the patient-centeredness dimensions), and since such factors influenced the effect of HCPs' efforts to provide PCC on patients' lived experiences, these factors are relevant in this research. Rathert, Wyrwich, and Boren (2012) described how, for example, a patient's condition and expectations can influence the effect PCC has on outcomes like patient satisfaction and clinical outcomes; further research could dive deeper into these relationships in the context of COVID.

Patients' physical as well as mental well-being were not only affected by the disease but also by specific care practices like intubation, the fixation of arms, heat-inducing gloves, and isolation. These care practices relate to what have been described as dehumanizing factors in intensive care (Brown et al. 2018; Wilson et al. 2019), which emphasizes the traumatic impact they can have. Physical restraint, although rather common in the ICU (Yönt et al. 2014), induces an ethical

dilemma consisting of HCPs' moral obligation to protect delirious patients from themselves (Mohr 2010) versus the fundamental human right of consent to medical activities that jeopardize one's physical or psychological integrity (McHale 2010). Recommendations from Wilson et al. (2019) to humanize care and facilitate connection are in line with facilitators for PCC identified in this research: physical touch, adequate communication (e.g., proper introductions and explanations of what is going to happen, even if a patient seems unresponsive), and allowing visitors.

Negative emotions like loneliness, fear, confrontation, and incomprehension that characterize patients' lived experiences enhanced their need to connect with family and HCPs. However, connection was complicated by several factors like isolation, which was generally experienced by patients as a heavy burden. Previous studies have shown that a lack of connection can have a discouraging and distressing effect on patients (Halldorsdottir 2008) and induce anxiety and even depression (Abad, Fearday, and Safdar 2010).

The essentiality of contact with loved ones as a source of support and motivation to overcome COVID became clear from the emotional intensity with which several patients talked about them and the frequency with which they used digital tools to stay in touch. According to Carlucci et al. (2020), such tools can humanize care by reducing distances and suffering. Although Cooley (2020) stated that digital tools can complicate connection by hindering non-verbal communication, paradoxically, during a communicable disease pandemic, it is precisely this digital technology that can facilitate connection (Zulman and Verghese 2021). This also applies to the care process, as these tools can facilitate intimate and interdisciplinary support from HCPs (Humphreys et al. 2020). They remove the need for PPE, allow for less rushed interactions and the mutual recognition of facial expressions (Schwamm et al. 2020), and "bring empathy back to the bedside" (Minor 2020). Pappot, Taarnhøj, and Pappot (2020) advocated for ongoing patient involvement in the development of these tools to ensure their applications are usable and meaningful.

Despite these communication tools and other strategies employed by HCPs to connect with patients, they were hampered by barriers like a lack of staff, time, and PPE. For example, patients' loneliness could be aggravated by the less frequent or shorter visits from HCPs to isolated patients (Abad, Fearday, and Safdar 2010). Clear communication and accommodating patients' information needs can be particularly important for patients infected with an unfamiliar disease, of which much is still unknown. Recent studies related to COVID-care recommend that HCPs are trained in psychological caregiving to improve their compassionate presence (Ferrell et al. 2020), attentiveness and companionship (He et al. 2020), and to encourage sources of patients' strength, self-care, and coping among patients in order to empower them and stimulate resilience (Brown et al. 2020). Furthermore, HCPs' training should target holistic, whole-person assessment and treatment, including spirituality (Ferrell et al. 2020).

PPE was experienced as a main barrier for several reasons. It negatively affected HCPs' patience and hindered patient visits due to the time needed for donning and doffing and by causing physical discomfort for HCPs. Besides, it impeded non-verbal communication and recognition of HCPs. This led to a certain impersonality of care, expressed in words like "Martians" and "surreal." Wearing masks can be negatively related to patients' perceptions of HCPs' empathy (Houchens and Tipirneni 2020), but transparent PPE seems a promising solution (Bernstein 2020; Sagar, Chawla, and Sen 2020).

Apart from this, PCC was also impeded by challenges in care coordination. These include the transfer of patients to other hospitals, fading motivation to explain matters to colleagues, and the different backgrounds and expertise of HCPs. These were not unique in our study. Shaban et al. (2020) also found that patients under infection-related contact restrictions have reported poor care coordination. Liu et al. (2020) concluded that inadequate coordination of COVID care could have been caused by the different organizational cultures and procedures in which HCPs were used. In line with the results of our study, Houchens and Tipirneni (2020) advised to stimulate collaboration through regular check-ins, updates, and (virtual) huddles with all team members.

Overall, the diverse and interrelated barriers found in this research, as well as in other studies, raise the question of whether providing PCC in a communicable disease pandemic is feasible. In such crises, the priority is simply to save as many people as possible. Patient-centeredness forms only one of the six quality of care dimensions that are endorsed by the Institute of Medicine (2001), and during the COVID pandemic, other quality dimensions like effectiveness and timeliness are at the forefront. Nevertheless, precisely in such a situation of insecurity and fear, PCC should be pursued to the extent possible. Several (innovative) facilitators identified in this research demonstrate that taking into account the diversity of patients' needs (in relation to their health as well as other areas like information) remains vital to promote their well-being during a pandemic like COVID.

Strengths and Limitations

The interviews took place via video calls or phone due to social distancing measures. Not being able to meet in person could have complicated building rapport (Deakin and Wakefield 2014; Weller 2017). However, Krouwel, Jolly, and Greenfield (2019) found video call interviews to yield a volume and breadth of data similar to the in-person alternative. The personal and sometimes emotional stories that participants shared (both via video calls and over the phone) indicated that rapport-building was not considerably impeded. The use of a participatory research method helped participants to convey emotions embedded in their lived experiences and to share what was important to them (Wang and Burris 1997). Another strength of this study is the inclusion of both HCPs' and patients' perspectives, as these complemented each other well.

A limitation of this research concerns the representativeness of the sample of ex-hospitalized patients. Six out of seven patients were female, whereas the majority of hospitalized COVID patients in the Netherlands were male (Rijksinstituut voor Volksgezondheid en Milieu 2020). A reason for this difference could be that women are more likely than men to participate in qualitative research (Robinson 2014) and to talk about their emotions as a coping strategy (Tamres, Janicki, and Helgeson 2002). Since the interviews focused on an emotionally turbulent time in patients' lives, this reasoning seems a relevant explanation. However, a possible impact on the generalizability of findings must be recognized. For instance, Hu et al. (2020) found being female to be a robust risk factor for insomnia, anxiety, and depression among COVID inpatients. Hence, future research should include a larger sample size in which patients and HCPs with different characteristics are more adequately represented and study differences in lived experiences between subgroups of patients and/or HCPs. For example, experiences regarding PCC might differ for ICU and non-ICU COVID patients, and older patients might experience the use of digital tools in caregiving differently than younger patients. Future research can thereby build on our exploratory research, which provides a general overview of barriers and facilitators for PCC for patients hospitalized with COVID.

Conclusions

This research has illuminated how aspects of COVID (care) put a strain on PCC for hospitalized infected patients in diverse ways. Despite HCPs' motivation and efforts and their focus on saving lives and complying with safety rules, these barriers to the patient-centeredness of care appeared to seriously compromise patients' physical as well as emotional well-being. To minimize these barriers, it is very important to act upon the facilitators that this research has identified (e.g., clear communication, training for HCPs in psychological caregiving, the use of digital technology to facilitate connection, and improving collaboration among caregivers). Ongoing reflection on and adjustment of care practices needs to occur while building upon accumulated and shared knowledge. For this purpose, lived experiences from patients and health care professionals themselves remain invaluable. Although the results of this research need to be interpreted or generalized with caution, they have provided insights with which patient-centered and holistic care and hence better overall patient well-being can be promoted during communicable disease pandemics, of which COVID might not be the last.

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