

# BARRIERS TO AND FACILITATORS OF FAMILY CAREGIVING OF PATIENTS WITH COVID-19 EARLY IN THE PANDEMIC

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**Background** In 2020, many family members were thrust into the role of caregiving for a relative with COVID-19 with little preparation, training, or understanding of the disease and its symptoms.

**Objectives** To explore the barriers to and facilitators of caregiving experienced by family caregivers of patients with COVID-19 who had been in intensive care in the pandemic's earliest months.

**Methods** In-depth qualitative interviews were conducted by web conference with 16 adults recovering at home after intubation for COVID-19 in an intensive care unit at a major academic medical center and their primary caregivers from March to August 2020 (N=32). Thematic qualitative analysis was done using Watkins' rigorous and accelerated data reduction technique with MAXQDA software.

**Results** Seven themes emerged regarding factors that facilitated or posed barriers to care: other health conditions that increased complexity of care, interactions and experiences in the health care system, COVID-19's proliferation into other areas of life, the psychological well-being of the patient-caregiver dyad, experience of support from the dyad's network, the role of caregiving in the dyad, and contextual circumstances of the dyad. The themes often included both barriers and facilitators, depending on the experience of the dyad (eg, feeling encouraged vs fatigued by their support network).

**Conclusions** Understanding how patients with COVID-19 and their caregivers experience illness management across the recovery journey can help clarify the COVID-19 caregiving process and identify intervention targets to improve overall health and well-being of the care dyad. (*American Journal of Critical Care*. 2023;32:431-439)

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**T**he COVID-19 pandemic resulted in about 147 000 hospitalizations per week during peak periods.<sup>1</sup> Rates of readmission and death following hospital discharge for COVID-19 are both high, with poor social support structures for patients noted as a key driver of readmissions.<sup>2,3</sup> Family caregivers are essential care partners who facilitate the recovery of recently hospitalized patients and reduce preventable readmissions.<sup>4-6</sup>

Family caregivers of patients with COVID-19 who are discharged from intensive care units (ICUs) may experience symptoms of psychological distress characteristic of post-intensive care syndrome-family (PICS-F; 1 in 3 family members of patients in ICUs with COVID-19 had PICS-F) with the added pandemic-related complications of decreased provider contacts, less bedside education, less available home support, and the need for physical distancing.<sup>7-10</sup> These pandemic-specific challenges most likely add a layer of stress to the patient-caregiver dyad that may negatively affect the mental and physical health needs of both. However, little is known about the family caregiving experience of managing a patient with COVID-19 before and after ICU discharge.

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Emerging literature on pandemic caregiving has predominantly focused on family caregivers of adults with chronic or disabling conditions during the pandemic and suggests that pandemic-specific challenges (eg, reduction in care to limit transmission, confusion on public health guidelines) are highly associated with caregiver stress, depressive symptoms, and loneliness.<sup>8,11,12</sup> The few studies that examine family caregivers of patients with COVID-19 who have been in the ICU emphasize the mental health experience or how post-COVID-19 clinics support family members.<sup>13-16</sup> Little consideration has been given to the specific barriers and facilitators for family caregivers of patients with COVID-19 who had been admitted to the ICU in the early months of the pandemic. This is critical, as family caregivers are central partners in helping the patient recover at home and stay out of overburdened hospitals. This study aimed to identify barriers to and facilitators of family caregiving that may serve as intervention targets to enhance patient and caregiver well-being in pandemic contexts, as well as in more typical critical care environments.

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#### Methods

Data were drawn from a dyadic study exploring the journeys before, during, and after hospitalization of patients with COVID-19 who were intubated in an ICU during their hospital stay in the early months of the pandemic and their family caregivers. The study was approved by the University of Michigan Institutional Review Board (HUM00158390, 12/04/19, HEART study) and follows its policies and the Helsinki Declaration of 1975 policies. The Consolidated Criteria for Reporting Qualitative Research<sup>17</sup> were used (see Supplemental Table 1, available online only at [www.ajconline.org](http://www.ajconline.org)). Patients and caregivers consented online to being recorded and interviewed (separately) through an online video conferencing platform and received a small stipend for participating.

#### Participants

Participants were recruited through a study website, and targeted phone calls were made by using a patient database (DataDirect). Patients were eligible if they

(1) were hospitalized for at least 3 days because of COVID-19, (2) received mechanical ventilator support in the ICU at some point during their hospitalization, (3) were discharged directly from hospital to home, and (4) had a family caregiver who assisted during their recovery. The sample included 16 dyads and 32 interviews conducted from March to August 2020. Interviews took place a mean of 90 days after discharge.

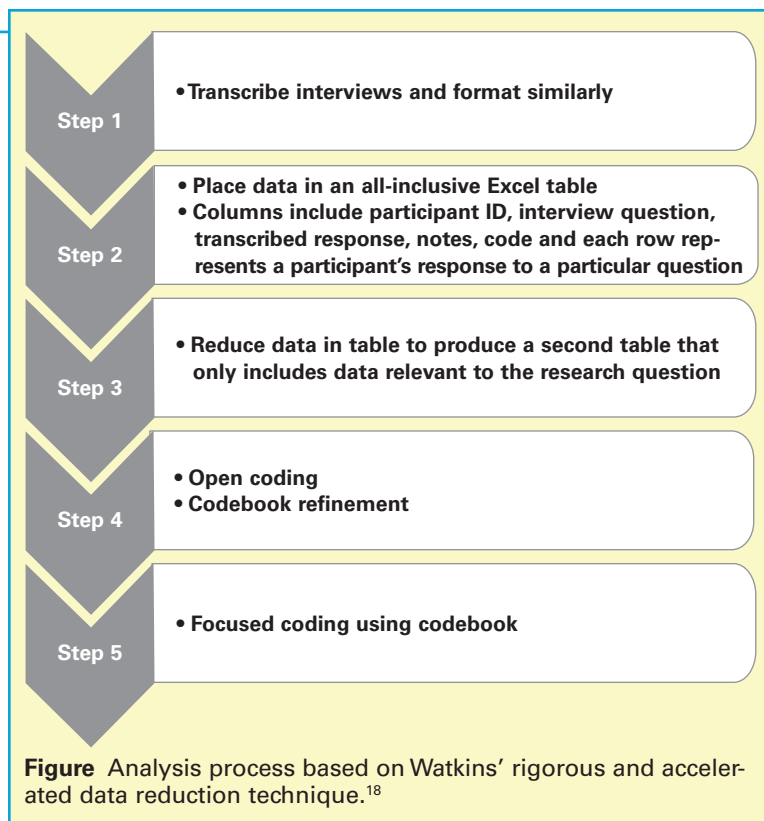
### Interview

In-depth, semistructured qualitative interviews (mean interview duration, 59.2 minutes; see Supplemental Table 2, available online only) covered the hospitalization experience; at-home recovery; the impact of physical distancing; support structures; and the impact of care on emotional, physical, and cognitive health. The lead author and trained research assistants conducted all interviews and met weekly during the interview phase to discuss field notes, themes, and data saturation. All interviews were recorded, transcribed, and had identifiable information redacted for analysis.

### Analysis

Thematic qualitative analysis was conducted through the iterative process of note-taking, coding, and consensus meetings undertaken by a team of 4 coders supervised and trained by the lead author. To reach the final themes, multiple steps were employed to ensure that the codes reflected the data. Watkins'<sup>18-20</sup> rigorous and accelerated data reduction technique for qualitative analysis was followed (see Figure). The process included researcher triangulation; diagramming and vetting of all codes, subthemes, and themes by a team of trained coders; alternating pairs of coders so that all pairs would code uniformly and not develop biases; maintaining records of all notes and discussions; use of the RADaR technique as a coding framework; and debriefing with the broader study team. MAXQDA (version 20.0.4), which is specialized software designed for organizing qualitative data, was used. The software flagged coding discrepancies, which were then resolved by coding pairs or brought to the broader team when necessary. Additional details are provided in Supplemental Table 1 (available online only).

The coding team first created a data table incorporating full transcripts from all interviews, then reached consensus on what text was relevant to the research question to achieve a more specific presentation of the transcripts for open coding. Next, the coding team open coded the data table, an iterative



process of developing, discussing, and refining codes aimed at identifying sections of text with overlapping concepts and commonality among participants.<sup>18-20</sup> Through this process, the coding team developed and iteratively refined a codebook consisting of codes, definitions, inclusion and exclusion criteria, and an example quote.

Finally, the coding team used the complete codebook for focused coding to solidify identified commonalities.<sup>18,20</sup> All discrepancies were resolved regardless of the percentage agreement (mean, 94.6%). Themes emerged during the process of grouping codes together around the common experiences of dyads (internal homogeneity). Themes incorporated both barriers to and facilitators of caregiving, and often one construct could be both. However, themes were distinct from one another (external heterogeneity). Conventional content analysis was used to see which codes were most frequent across the themes.<sup>18,21,22</sup> Additional details on rigor and trustworthiness are noted in Supplemental Table 1 (available online only).

**Family caregivers of patients with COVID-19 who are discharged from ICUs may experience symptoms of psychological distress with added pandemic-related complications.**

**Table 1**  
**Sample characteristics**

| Characteristic                         | Caregivers<br>(n = 16) | Patients<br>(n = 16) |
|--|------------------------|----------------------|
| Age, mean (SD), y                      | 54.4 (13.3)            | 57.6 (13.2)          |
| Sex, No. (%)                           |                        |                      |
| Male                                   | 4 (25)                 | 12 (75)              |
| Female                                 | 12 (75)                | 4 (25)               |
| Race and ethnicity, No. (%)            |                        |                      |
| Non-Hispanic Black or African American | 4 (25)                 | 4 (25)               |
| Non-Hispanic White                     | 9 (56)                 | 10 (62)              |
| Multiracial/multiethnic                | 1 (6)                  | 1 (6)                |
| Hispanic                               | 2 (12)                 | 1 (6)                |
| Education, No. (%)                     |                        |                      |
| High school degree or GED              | 4 (25)                 | 0 (0)                |
| Some college or associate's degree     | 4 (25)                 | 8 (50)               |
| Bachelor's degree or higher            | 8 (50)                 | 8 (50)               |
| Annual household income, No. (%)       |                        |                      |
| <\$50 000                              | 2 (12)                 | 3 (19)               |
| \$50 000 to \$74 999                   | 2 (12)                 | 3 (19)               |
| \$75 000 to \$99 999                   | 2 (12)                 | 2 (12)               |
| ≥\$100 000                             | 6 (38)                 | 5 (31)               |
| No response                            | 4 (25)                 | 3 (19)               |
| Employment, No. (%)                    |                        |                      |
| Full time                              | 10 (62)                | 10 (62)              |
| Not employed                           | 5 (31)                 | 6 (38)               |
| No response                            | 1 (6)                  | 0 (0)                |
| Relationship to patient, No. (%)       |                        |                      |
| Spouse or significant other            | 13 (81)                |                      |
| Parent                                 | 1 (6)                  |                      |
| Adult child                            | 1 (6)                  |                      |
| Sibling                                | 1 (6)                  |                      |

Abbreviation: GED, General Educational Development test.

## Results

Demographic characteristics for the sample can be found in Table 1. Table 2 presents the 7 identified themes with their component-focused codes, the frequency of use of each code across the 32 transcripts, and representative quotes. Each of the 7 themes are described next.

### Other Health Conditions Made Caregiving More Challenging

Both patients and caregivers commonly had health conditions beyond COVID-19 (eg, kidney disease, torn quadriceps tendon) that compromised immune systems or made physical caregiving more difficult. Several caregivers themselves were COVID-positive before or during their care provision, though their symptoms were less severe, and a few were even hospitalized with COVID-19. This necessitated caretaking while physically isolating from others. One caregiver (ID 0152964) facilitated her husband's admission to the hospital from her own hospital bed. Caregivers often struggled to provide the complex care that was

needed while dealing with their own health issues or COVID-19 symptoms.

### The Impact of the Health Care System on Caregiving

Caregivers and patients discussed how health care guidelines constantly changed in the early months of the pandemic, leaving caregivers uncertain about how to provide care. However, the major focus of this theme was barriers to and facilitators of health care access and support by the care team. The emotional and care-related support provided by health care staff facilitated care; yet, almost as commonly, the dyads expressed a lack of needed support from health care staff making care more difficult, especially with hospital visitation restrictions for caregivers. One caregiver described being given the phone number of the ICU nurse but having trouble contacting her: "At one point [the nurse] answered it and put the phone in her pocket and . . . went on her [way]. So, we really didn't have any access." (ID 0154553)

Lack of access to or satisfaction with care (eg, inability to go to rehabilitation), or a lack of or wish for access to formal care (eg, waiting list for physical therapy, not being admitted because of COVID-19-status) was commonly described. This affected caregiving as it delayed recovery and placed burden on the caregiver to find available services and support rehabilitation at home. Access was also facilitated by someone from the health care team referring the patient for hospital or outpatient care. Thus, the quality of patient care and accessibility of services was hampered or aided by health care professionals, which in turn had a direct impact on caregivers' medical decision making, access to information about the caregiving, and availability of needed services.

### COVID-19's Proliferation Into Other Areas of Life

Caregivers were tasked with taking precautions to support the health of the patient while striving to reduce their own risk and that of other family members (eg, cleaning every time the patient used the bathroom, wearing personal protective equipment while providing care, not accepting help from others because of physical distancing). Such precautions led to the experience of isolation: isolation of the patient and caregiver from one another during hospitalization as well as isolation of the dyad from their usual support systems due to their COVID-19 status. Stigma was a unique feature of COVID-19 caregiving, in which dyads experienced negative reactions from others due to the COVID-19 infection. Caregiver

**Table 2**  
**Representative quotes from each theme**

| Theme  | Code                           | Total use <sup>a</sup> | CG use <sup>b</sup> | CR use <sup>c</sup> | Representative quotes   |
|--|--------------------------------|------------------------|---------------------|---------------------|---|
| Other health conditions that made caregiving more challenging        | Health problems CG             | 11                     | 3                   | 2                   | Barrier and facilitator: [Caregiver] called 911 from my hospital bed . . . and I went, "Sir! I'm in my COVID bed at [Health System]! My husband is dying and can't breathe! He can't breathe at home!" . . . and she says, "Didn't we just extract somebody from that home a week ago?" "I went yeah, that's me." (ID 0152964)<br><br>Barrier: I did not want to go home without the [COVID] testing because my wife's [caregiver's] immune system is shut down due to hemodialysis. (ID 1241938) |
|  | Health problems CR             | 27                     | 4                   | 8                   |   |
|  | CG had COVID-19                | 17                     | 3                   | 4                   |   |
| The impact of the health care system on caregiving                   | Formal care access barrier     | 48                     | 6                   | 9                   | Barrier: [Patient] was discharged with some paperwork and . . . it was really vague and didn't really give me much to go off of. (ID 0154553)   |
|  | Formal care access facilitator | 54                     | 8                   | 10                  |   |
|  | Care team absence              | 52                     | 8                   | 9                   | Facilitator: My nephrology transplant team would call [patient] every day and see how my progression was going . . . they made the decision for the admit to the hospital. We never called them. [ID 1103406]   |
|  | Care team support              | 116                    | 12                  | 14                  |   |
|  | Referrals                      | 17                     | 6                   | 5                   |   |
|  | Lack of information            | 99                     | 12                  | 12                  |   |
| COVID-19's proliferation into other areas of life                    | Stigma                         | 34                     | 5                   | 5                   | Barrier: And nobody was coming over. Twice, [caregiver] got a phone call . . . And I weaned myself off the oxygen myself with no help from anyone else. I mean, no one. No one . . . It was like you were the plague. That's kind of how I felt. (ID 0224474)<br><br>Barrier: She had to glove up and mask up and clean like crazy . . . and it created a lot of work for [caregiver]. (ID 1240221)   |
|  | COVID-19 precautions           | 83                     | 12                  | 13                  |   |
|  | Isolation                      | 37                     | 6                   | 11                  |   |
| Psychological mindset and mental state                               | Negative mindset               | 23                     | 7                   | 6                   | Barrier: I was trying to be as empathetic as possible and making myself available to [patient] . . . care take as best I could. You know crying and screaming after some nights because . . . I didn't understand. I thought she [would] come out [of the hospital] and be happy to be alive and she came out and it was like whoa. (ID 0154553)  |
|  | Positive mindset               | 79                     | 12                  | 11                  |   |
|  | Loneliness                     | 21                     | 5                   | 6                   | Facilitator: It's just part of your relationship when one is leaning on one more than the other at the time . . . it's just what you do, you know, and I'm glad to do it. (ID 0224474)  |
|  | Mental health CG               | 48                     | 12                  | 5                   |   |
|  | Mental health CR               | 85                     | 10                  | 11                  |   |
|  | Uncooperative                  | 42                     | 11                  | 8                   |   |
| The support system's assistance and feelings related to that support | Contact fatigue                | 17                     | 5                   | 5                   | Barrier: I said so many people checked on me, but it was overwhelming, and it kept me awake when I couldn't sleep because my phone kept going off and I should have just turned it off but [patient] was in the hospital, so I couldn't. (ID 1240221)   |
|  | Feeling supported              | 141                    | 12                  | 16                  |   |
|  | Emotional support              | 132                    | 13                  | 16                  |   |
|  | Refusal/reluctance             | 40                     | 11                  | 6                   | Facilitator: Even [patient's] friends would be texting me and . . . they'd say, "and how are you?" . . . "Do you need anything?" . . . Countless offers to pick any food up, to drop it off. (ID 521451)  |
|  | Instrumental support           | 111                    | 15                  | 16                  |   |
|  | Delegation                     | 40                     | 9                   | 6                   |   |
|  | Spirituality/faith             | 48                     | 7                   | 7                   |   |
| The caregiving role in the dyad                                      | CG deprioritization            | 43                     | 12                  | 7                   | Barrier: It takes a toll on your body . . . you're not used to doing all of this, then all of a sudden you have to do it with a smile. Even though you're in pain or you're not sleeping well . . . you have to hide it. (ID 0144604)   |
|  | CG prioritization              | 9                      | 3                   | 2                   |   |
|  | CG/CR comm barrier             | 92                     | 13                  | 14                  |   |
|  | CG/CR comm facilitator         | 63                     | 13                  | 13                  | Facilitator: [The caregiver] kind of took control . . . I mean, I'm going to the pulmonologist's, and she will be there . . . She already has sat down and written out some questions to ask, stuff that I didn't even think of . . . she's definitely in the lead. (ID 1521452)  |
|  | Reliance                       | 64                     | 10                  | 11                  |   |
|  | Patient advocacy               | 76                     | 11                  | 11                  |   |

*Continued*

**Table 2**  
**Continued**

| Theme                    | Code                        | Total use <sup>a</sup> | CG use <sup>b</sup> | CR use <sup>c</sup> | Representative quotes   |
|--------------------------|-----------------------------|------------------------|---------------------|---------------------|---|
| Contextual circumstances | Circumstance barrier        | 25                     | 7                   | 7                   | Barrier and facilitator: So fortunately, my husband has very good insurance and we've seen some of the hospital bills come through and what's been paid out, and it's crazy, crazy dollars. But . . . we had to spend several hundred dollars on a few prescriptions that weren't covered because there wasn't prior approvals on [them], and I find that disturbing, because he didn't have this problem before he had COVID. And now that he's had COVID and it's created this problem, we've had to undergo additional expenses and the insurance didn't seem to care. (ID 0106530)<br>Facilitator: I joined a Facebook group for COVID survivors this week, and reading all of their things that they're going through and offering suggestions and sharing stories has helped tremendously . . . because there's a lack of information. (ID 1240221) |
|                          | Circumstance facilitator    | 101                    | 15                  | 13                  |   |
|                          | DME barrier                 | 31                     | 7                   | 7                   |   |
|                          | DME facilitator             | 63                     | 10                  | 12                  |   |
|                          | Economic barrier            | 22                     | 4                   | 7                   |   |
|                          | Economic facilitator        | 34                     | 9                   | 7                   |   |
|                          | Environmental barrier       | 21                     | 4                   | 6                   |   |
|                          | Environmental modifications | 34                     | 6                   | 8                   |   |
|                          | Technology barrier          | 18                     | 2                   | 6                   |   |
| Technology facilitator   | 103                         | 16                     | 13                  |                     |   |

Abbreviations: CG, caregiver; comm, communication; CR, care recipient; DME, durable medical equipment.

<sup>a</sup> The number of times the code was applied across all transcripts.

<sup>b</sup> How many of the 16 caregivers had a code applied anywhere within their transcript.

<sup>c</sup> How many of the 16 care recipients had a code applied anywhere within their transcript.

0224474, who also had COVID-19, noted the feeling of isolation and stigma simultaneously: "Nobody was coming over. . . . I weaned myself off the oxygen myself with no help from anyone else. . . . It was like you were the plague."

### Psychological Mindset and Mental State

The psychological mindset and mental state of the dyad, which encompassed feelings of depression, anxiety, worry, guilt, and burden related to the hospitalization and recovery process, affected how the caregiver provided care. One caregiver talked about the

dyad's mental health concerns openly, saying: "We're both going to need some psychotherapy. . . . I think we both have PTSD." (ID 0152964)

Often these mental health challenges were brought on by a feeling of loneliness. One patient (ID 1226314) stated that they would rather be dis-

charged and die at home than remain separated from family in the hospital. Participants varied in their mindsets, from positive (eg, optimism, determination) to

negative (eg, pessimism, mistrust), which influenced caregiving and goal-setting. Caregivers described knowing that providing care was part of a familial relationship and feeling the need to push through even when they did not feel like it. Caregivers also struggled with patients being uncooperative and unwilling to work with the care team or caregivers themselves to facilitate recovery. Patients would sometimes resist formal care (eg, physical therapy) or resist the caregiver's assistance but cooperate with the formal care team, which led to frustration for the caregiver.

### Assistance From the Support System and Feelings Related to That Support

The dyads emphasized the importance of support received and offered from their familial and social networks, yet also described ways that support was overwhelming or prevented focus on their care responsibilities. Reports of instrumental support (eg, help with housework, groceries) and emotional support (eg, offers of encouragement) were common, and caregivers found it beneficial to know they were supported regardless of the amount of support received. Caregivers found it helpful to delegate tasks and share care-related decision-making with other family and friends (eg, having certain family members receive the medical updates or contact family and friends so the caregiver could prioritize caregiving). Despite this, many caregivers also experienced contact fatigue whereby they felt overwhelmed by the outpouring

Other health conditions made caregiving more challenging (eg, several caregivers themselves were COVID-positive before or during their care provision, though their symptoms were less severe, and a few were even hospitalized with COVID-19).

of calls, text messages, and social media (which contrasts with the physical separation described regarding “stigma” and “loneliness” as a result of quarantine). One caregiver (0240221) described how constant check-ins from family and friends kept her from sleeping and yet she had to keep her phone on in case someone called from the hospital. Yet some dyads refused or were reluctant to accept any care-related supports—whether from health care providers, family/friends, or the caregiver themselves (eg, a patient preferring to do a care task themselves, reluctance to accept food that might be contaminated). Finally, caregivers viewed their personal experience of support through faith or religion as benefiting their outlook on care (eg, prayer, visitation by a chaplain). Caregivers functioned as gatekeepers and delegators for all forms of support, yet at times this was frustrating when offers of support deemed necessary were turned down by the patient.

### The Caregiving Role in the Dyad

The dyads discussed their reliance on one another, particularly the patient’s dependence on the caregiver given physical weakness from hospitalization and lingering COVID-19 symptoms. Caregiver 0106530 described,

When I took him to the hospital, he was a very active 210-pound man. Bringing him home he was in a wheelchair, 40 pounds lighter, and could [only] walk very short distances . . . needed 100% of my help at all times.

Caregivers also advocated on the patient’s behalf (eg, to have the patient seen or admitted to the hospital or to receive quality care). In handling this strain of care, caregivers found they had instances where they deprioritized their own needs to focus on the patient, and other times where they needed to prioritize their own well-being. Sometimes this deprioritization or prioritization was action focused (eg, prioritizing dyadic relationship, making sure the patient had the best care possible), whereas other times deprioritization or prioritization aligned with the “psychological mindset” theme in mentally prioritizing the patient or oneself. Dyads also described their ability or inability to communicate at the dyadic level, particularly during hospitalization, as both beneficial and problematic to caregiving and working as a team. Communication was hampered at the dyadic level when the patient was in the ICU or when the patient was delirious, yet technology facilitated communication in the hospital through video calls and text messaging.

### Contextual Circumstances

Socioeconomic and other contextual circumstances affected the care environment. Technology was a primary focus, either the dyad’s dissatisfaction with it (eg, hospital phones) because it made dyadic communication more difficult, or its ability to aid the dyad in staying connected (eg, search for caregiving tips, telehealth). Caregivers described circumstances that made care easier (eg, knowing someone who worked in the hospital where the patient was) or more difficult (eg, the patient’s weight making physical care challenging). One caregiver (ID 0154553) described how her aunt, a medical professional, would help guide her on next steps to take in caregiving. The dyad’s employment or financial circumstances (eg, health insurance, paid leave, socioeconomic status) aided or impeded caregiving. The home environment also posed challenges to care (eg, stairs, long hallways), yet caregivers were creative in their environmental modifications to enhance their caregiving ability (eg, adding ramps or toilet seat risers to facilitate patient’s mobility, using a different bathroom that fit a walker, placing a chair in a hallway as a resting point). Often durable medical equipment was brought into the home to assist recovery of the patient, such as oxygen, shower chairs, or walkers. Yet sometimes the durable medical equipment posed difficulties such as the lack of available equipment due to supply chain issues, not receiving training on use, or the heaviness and bulkiness of the equipment making mobility more cumbersome.

Lack of access to or satisfaction with care, or a lack of or wish for access to formal care, was commonly described.

### Discussion

The current study examined patients with COVID-19 who had been hospitalized and intubated and their caregivers at the onset of the pandemic in the United States with a dyadic sample that enabled exploration of the full journey from first experiencing symptoms through hospitalization and recovery at home. As there were periods when the patients and caregivers were isolated from each other, both caregiver and patient data were included to bring their unique perspectives on the care environment. Many challenges faced by caregivers of patients with COVID-19 were related to the pandemic context (eg, isolation, lack of discharge instructions), whereas others were similar to the challenges faced by caregivers of patients with other chronic or disabling conditions

(eg, stigma and fluid care roles have similarities to the experiences of HIV/AIDS caregivers).<sup>23-26</sup>

Our themes are transferable and build on recent studies regarding patients with COVID-19 and family care.<sup>27-31</sup> For example, studies with general caregiving samples or patients with COVID-19 who were not hospitalized showed that stigma, loneliness, and socioemotional support affected the patient recovery process. Caregivers placed new emphasis on safety and vigilance in their care practice and connecting with friends and family was often facilitated through technology.<sup>27-29</sup> Studies on COVID-19 also suggest increased psychological disturbances relative to non-caregivers, particularly among those with low family contact.<sup>30,31</sup> These findings

align with our themes of the importance of the support system, impacts of COVID-19 in multiple aspects of life, and one's psychological mindset and mental state. Yet our data point to nuance not identified in existing literature, such as caregivers also having COVID-19, experiencing stigma as a result of the patient's diagnosis, dyadic decision making on accepting external support, and the influence of dyadic communication, advocacy, and deprioritization and prioritization on the recovery process and mental health.

Study themes relate to broader socioecological theoretical models in which the environments around an individual interact to influence outcomes. For example, we saw interactions between caregivers and health care systems through caregiver advocacy on behalf of the patient and through lack of support resulting from a lack of discharge instructions or training on posthospital care provision.<sup>32</sup> COVID-19 introduces new factors with implications for socioecological models, including changing availability of health care and services, rapidly evolving information on COVID-19, care precautions specific to transmission, physical distancing, stigma, social policies changing economic and community structures, and even supply chain issues.

Therefore, intervening upon modifiable factors at multiple environmental levels may bolster informal care provision and reduce preventable outcomes (eg, COVID-19 complications, rehospitalization). For example, international programs (eg, THRIVE,

InS:PIRE) that provide peer support and integrated social and health care for care dyads after ICU discharge are associated with significant improvement in caregiver strain and psychological well-being as well as patient quality of life.<sup>33-36</sup> Facets of existing programs that patients who have been admitted to ICUs have found helpful include normalizing the disease process (a challenge as there were many unknowns with COVID-19 in the early months), continuity of care, validating patient progress, ongoing management of physiological disturbances, and continuing support programs for caregivers.<sup>37</sup> Our findings also suggest COVID-19-specific modifications that may be helpful, such as incorporating caregivers into bedside learning or the patient discharge meeting through video-based technologies, as has been efficacious in person.<sup>38</sup>

### Limitations

Our sample was small and drawn from one university-based health care system; thus, our participants may not be representative of patients who have been hospitalized with COVID-19 and their caregivers from other areas of the country. Our sampling was done at the start of the pandemic and thus our data may be different from those collected during later waves of the COVID-19 pandemic. Cognitive impairment resulting from PICS-F could affect recall of some participants after a traumatic hospitalization. However, our study is unique in that the transcripts of caregiver and patient dyads were analyzed together to offer insights that would have been missed in separate studies of caregivers or patients.

### Conclusions

In-depth qualitative interviews with patients with COVID-19 who had been intubated and subsequently recovered at home and their family caregiver identified a variety of barriers to and facilitators of pandemic caregiving. Themes were internal, network-based, health system-specific, or contextual, suggesting efforts to enhance informal COVID-19 care and improve well-being must take barriers and facilitators at multiple socioecological levels into account. As understanding of COVID-19 and its long-term effects has grown, and with new COVID-19 variants on the rise, enhancing families' ability to provide care, find social support, and maintain well-being has potential for great public health impact.

### FINANCIAL DISCLOSURES

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Many challenges faced by caregivers of patients with COVID-19 were related to the pandemic context, whereas others were similar to the challenges faced by caregivers of patients with other chronic or disabling conditions.



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