DOI: 10.1002/jhm.12924

ORIGINAL RESEARCH



Patients' and caregivers' experiences of hospitalization under COVID-19 visitation restrictions

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Funding information

Northern New England Clinical & Translational Research Network, Grant/Award Number: NNE-CTR Mini-pilot awards on Covid-19 projects

Abstract

Background: During the COVID-19 pandemic, hospitals did not allow caregiver visitation. Little is known about how caregivers' absence affected patients' care. **Objective:** This study aimed to describe visitation restrictions' impact on patients and their caregivers experiences.

Design: We used a sequential explanatory mixed-methods study design. First, we randomly selected 200 adult patients with cancer or heart failure hospitalized before (n = 100) and during visitor restrictions (n = 100) and abstracted data from the electronic medical record on communication between medical teams and caregivers and the topics discussed. Results from the quantitative analysis guided our thematic analysis of semi-structured interviews conducted with a subsample of patients hospitalized during visitor restrictions and their caregivers to understand the impact of visitor restrictions on their experiences.

Results: Compared to prerestrictions, caregivers under visitation restrictions communicated less frequently with the medical team (29% vs. 37% of hospitalized days; p = .04), fewer received discharge counseling (37% vs. 52%; p = .04), and disproportionately more had *no* contact with the medical team (36% vs. 17%; p < .01). Video conferencing was documented for caregivers of only five patients. Qualitative analysis revealed that both caregivers and patients experienced emotional distress, increased conflict, and decreased perception of quality of care because of visitation restrictions.

Conclusions: Hospital visitor restrictions significantly reduced caregivers' communication with patients' medical team, causing caregivers and patients emotional distress. Protocols that facilitate communication between caregivers and care teams may benefit caregivers who cannot be physically present at care facilities, including distance caregivers.

INTRODUCTION

Patients depend on family, friends, or other informal caregiver(s) to navigate acute hospitalizations. Caregivers facilitate communication with care teams, collect and process information, advocate for patients, and aid medical decision-making.¹⁻³ The presence of caregivers is associated with lower odds of medication errors and withholding necessary treatment,⁴ and improved transition home.^{5,6} Caregivers' involvement is also linked to patient and caregiver well-being and less bereavement.⁷⁻⁹

Hospital visitors were restricted during the COVID-19 pandemic,¹⁰ and early evidence suggests that restrictions negatively impacted patients' and caregivers' well-being.¹¹⁻¹⁴ Few studies have assessed the impact of visitor restrictions on caregivers' communication with the medical team or the potential effect on care quality and patients' and caregivers' experiences.¹⁵⁻¹⁷

We conducted a sequential explanatory mixed-methods study of the impact of visitor restrictions on care teams' communication with patients and their caregivers. Research questions investigated whether and how visitor restrictions impacted (1) care teams' communication with "remote" caregivers and (2) patient and caregiver hospitalization and discharge experiences.

DATA AND METHODS

We used a sequential explanatory mixed-methods study design, a two-phase design, where results from quantitative analyses of Phase 1 informed the direction of the qualitative analysis of Phase 2 of our study.¹⁸

Phase 1–Quantitative analysis

We reviewed electronic medical record (EMR) charts for 200 randomly selected patients admitted for oncology or heart failure exacerbation for 3+ days to Maine's largest health system. We included patients admitted before (n = 100; pre-March 24, 2020) and during visitor restrictions (n = 100; March 25, 2020 to May 30, 2020). We selected an early pandemic period when Maine's COVID-19 hospitalization rates were low,¹⁹ so potential care differences were less likely due to staff overwhelmed by COVID-19 patients. We stratified sample selection by gender, diagnosis, and age using Stata's "sample" procedure,²⁰ sampling patients until both phases (before and during restrictions) were 50% female, rural residents, had a cancer diagnosis, and were at least 70 years old. We oversampled older patients because they are more likely to have involved caregivers.

EMR abstraction

The study team—a palliative care physician (R. N. H.), two palliative care fellows (S. S. and J. B.), a medical sociologist (A. F.), an anthropologist (M. K.), and a medical student (Z. C.)—identified and defined measures to abstract from EMRs (see Supporting Information: Appendix). Z. C., S. S., and J. B. abstracted EMR data using RedCap.²¹ To ensure interreviewer consistency, two reviewers reviewed 10% of charts (n = 20) and agreed on 99.95% of the 17,080 data points collected. We resolved any reviewer's uncertainties about data classification via team consensus during weekly meetings.

We defined caregivers as family members or friends who lived with the patient, received the patient at discharge, were contacted during the admission, were listed as a healthcare power of attorney, or provided some form of documented physical or emotional support during hospitalization. We excluded patients with no caregiver mentioned (three hospitalized before restrictions, three hospitalized during restrictions).

We abstracted data on three communication measures and patient outcomes.

Communication measures included the following:

- Medical team contact with caregiver: Any documented communication between the caregiver and the medical team during hospitalization. We calculated contact frequency as the percent of hospitalized days a caregiver was contacted at least once.
- Discharge counseling: Any documented communication between the caregiver and the medical team on the day of, or the day prior to, discharge and, if so, the topics discussed (e.g., medication counseling, basic care, limitations). Topic categories were modeled after described best practices at hospital discharge.²²
- Goals of care (GOC) conversations: Documented interactions between the patient or the caregiver and the patient's medical provider regarding any of the following: prognosis, patient's goals and values, end-of-life care planning, and life-sustaining treatment preferences.²³

We also documented any mention that the medical team used video conferencing to communicate with caregivers.

Statistical analysis

Since potential confounding by gender, rurality, age, and disease type was addressed by stratification, we assessed the association of visitor restrictions with communication using two-sided *t*-tests. $p \le .05$ were considered statistically significant.

Qualitative interviews

To improve our interpretation of findings from the quantitative data analysis, we interviewed a subsample of the patients hospitalized during visitor restrictions and their caregivers.²⁴ We excluded patients with hospitalizations less than 5 days (n = 29) to ensure that we interviewed caregiver-patient dyads with substantial communication needs due to complex care. After excluding non-English speakers (n = 1) and patients with severe mental illness (n = 5) or cognitive impairment (n = 9), we sent mailers explaining the study to the 53 remaining patients or their bereaved caregiver. Patients who contacted study staff to participate and consented provided their caregiver's contact details for recruitment.

Interviews were conducted by phone by a cis-gender male anthropologist, lasted 30–60 min, were audio-recorded, and transcribed for analysis. Using "building" to examine potential quantitative findings,²⁴ interviews entailed open-ended questions, often catered to probe data from their chart, about the caregiver's/patient's

2

communication experience during hospitalization, and subsequent discharge (see the Supporting Information Appendix for interview guides). Participants received a \$25 gift card. All study procedures were approved by Maine Medical Center's institutional review board.

Analysis

Interview transcripts were analyzed using thematic analysis, a flexible qualitative analysis approach to identify and evaluate patterns in data.²⁵ To do so, the study team read and then open-coded transcripts line by line and wrote memos using MAXQDA 2020 software.²⁶ In the resulting codebook, we organized codes by themes, which related to caregivers' and patients' communication experiences, their met and unmet communication needs, and the perceived impact on patient outcomes, caregivers' and patients' emotional well-being, and perceptions of care quality. Thematic saturation was not reached due to limited sample size. For all transcripts, the team met regularly during the analysis to systematically compare and discuss discrepancies between their independent application of codes as the codebook evolved.

RESULTS

Sample characteristics

Characteristics used to stratify samples (gender, rurality, diagnosis, age) did not vary by visitor restrictions phase (Table 1). In each phase's sample, approximately half of the patients were female (50% vs. 47%; p = .78), at least 70 years old (46% vs. 60%; p = .67), had a cancer diagnosis (53% vs. 49%; p = .57), and resided in a rural area (49% vs. 50%; p = .57). The proportion of married patients (51% vs. 49%; p = .79), those who identified as White (94% vs. 97%; p = .30), or caregivers' relation to the patient varied by phase.

Association of visitor restrictions with communication

Caregivers of patients hospitalized during visitation restrictions communicated less with medical teams than caregivers of patients hospitalized before restrictions. Medical teams contacted these caregivers less (29% vs. 37% of hospitalized days; p = .04; Table 2) or not at all (36% vs. 17% of caregivers were not contacted; p < .01). Additionally, fewer caregivers received discharge counseling during restrictions (37% vs. 52%; p = .04). Discharge counseling was also less comprehensive: fewer caregivers received guidance about basic care and limitations (10% vs. 32%; p < .001), anticipatory guidance (7% vs. 25%; p < .001), medication counseling (6% vs. 29%; p < .001), and follow-up appointments (14% vs. 27%; p = .02). There were no statistical differences in the frequency of GOC discussions or their content.
 TABLE 1
 Characteristics of patients by visitor restriction status

	Visitor restrictions (n = 97)		No restrictions (n = 97)		
Measures	N	%	N	%	p Value
Gender					
Female	48	49.5	46	47.4	.78
Male	49	50.5	51	52.6	
Age					
Less than 70	45	46.4	48	49.5	.67
70 or older	52	53.6	49	50.5	
Rurality					
Metro	54	50.9	49	50.5	.57
Rural (large/small/ isolated rural area)	52	49.1	48	49.5	
Diagnosis					
Cancer	51	52.6	47	48.5	.57
Advanced heart failure	46	47.4	50	51.5	
Race					
White	90	93.8	94	96.9	.3
Non-White	6	6.3	3	3.1	
Marital status					
Married/partnered	49	50.5	47	48.5	.79
Not married (divorced, single, widowed, separated)	48	49.5	50	51.5	
Caregiver relation to patient ^a					
Spouse/significant other	50	51.5	51	52.6	.89
Child	49	50.5	50	51.5	.89
Other family	21	21.6	25	25.8	.50
Friend	2	2.1	7	7.2	.09
Formal caregiver	0	0.0	2	2.1	.16

^aPercent of caregivers sums to greater than 100% since patients could have multiple caregivers.

Impact of visitor restrictions on caregiver and patient experiences

We conducted interviews with at least one member of nine patient-caregiver dyads (six caregivers and seven patients), providing a 17% recruitment rate (9 of 53 dyads). Respondents included four patients and their caregiver-spouses, two caregivers whose parent-patient had died during or shortly after the hospitalization, and three patients whose caregivers could not be reached or did not consent to be interviewed. Recruitment yielded a small sample that did not reach thematic saturation since participants had to initiate

TABLE 2 Results of t-tests comparing percent of patient and caregiver experiences by visitor restriction status

	Visitor restrictions		No restrictions		
Measures	%	95% CI	%	95% CI	p Value
Medical team contact with caregiver					
Contact frequency (percent of hospitalized days contacted)	28.6	22.7-34.6	37.3	31.2-43.4	.04
No contact	36.1	26.4-45.8	16.5	9.0-24.0	.002
Goals of care conversation					
Conversation occurred	54.6	44.6-64.7	44.3	34.3-54.4	.15
Goals and values discussed	32.0	22.5-41.4	32.0	22.5-41.4	1.00
Prognosis/illness understanding discussed	29.9	20.6-39.2	35.1	25.4-44.7	.45
EOL care planning discussed	27.8	18.8-36.9	21.7	13.3-30.0	.32
Life-sustaining treatment options discussed	38.1	28.3-48.0	33.0	23.5-42.5	.46
Change between admission and discharge code status ^a	16.7	9.1-24.3	10.8	4.3-17.2	.24
Discharge counseling ^a					
Caregiver contacted at discharge	36.5	26.7-42.3	51.6	41.3-62.0	.04
Topic discussed with caregiver and/or patient at discharge					
Basic care and limitations	61.5	51.6-71.4	67.7	58.1-77.4	.37
Anticipatory guidance	37.5	27.6-47.4	45.2	34.9-55.5	.29
Assessing whether additional support is needed	46.9	36.7-57.0	39.8	29.7-49.9	.33
Explanations of tests, procedures, prognosis	25.0	16.2-33.8	32.3	22.1-35.1	.27
Medication counseling	54.2	44.0-64.3	59.1	49.0-69.3	.49
Follow-up appointments	63.5	53.7-73.4	61.3	51.2-71.4	.75
Emotional support	5.2	6.8-9.7	5.4	0.7-10.1	.96
Logistics only	11.5	5.0-18.0	11.8	5.1-18.5	.94
Topic discussed with caregiver					
Basic care and limitations	10.4	4.20-16.6	32.3	22.6-41.9	.000
Anticipatory guidance	7.3	2.0-12.6	24.7	15.8-33.7	.001
Assessing whether additional support is needed	19.8	11.7-27.9	25.8	16.8-34.9	.33
Explanations of tests, procedures, prognosis	15.6	8.2-23.0	20.4	12.1-28.8	.39
Medication counseling	6.3	1.3-11.2	29.0	19.6-38.4	.000
Follow-up appointments	13.5	6.6-20.5	26.9	17.7-36.1	.02
Emotional support	2.1	-0.8 to 5.0	4.3	0.1-8.5	.39
Logistics only	11.5	5.0-18.0	7.5	2.1-13.0	.36

Abbreviations: CI, confidence interval; EOL, end-of-life.

^aPatients who died in hospital are excluded.

contact after mailers. Our qualitative findings are therefore exploratory.

Patients described feeling isolated without their caregiver(s). As Patient 8 explained, "Do you know how lonely that is? To be in a hospital for 10 days and none of your family comes to visit you?" Some patients also described missing their caregivers' encouragement: "She really is my motivator. She gets me going when no one else can, and that was part of what I missed when she wasn't in the hospital" (Patient 2). As detailed below, interviews also offered insight into the quantitative analyses' results. Respondents described how caregivers' limited contact with the care team hindered caregivers' ability to assess patients' well-being and advocate for them. Similarly, the reduced discharge counseling restricted caregivers' information gathering about posthospitalization care needs and continuity. Ultimately, many caregivers and patients reported that caregivers' diminished capacity to advocate and gather information caused them emotional distress and impacted perceived care quality. We also

found evidence of conflicting communication with caregivers about visitation restrictions that created additional emotional distress.

Limited access to information and ability to advocate

Since, without being physically present, caregivers relied on unpredictable opportunities to connect with medical staff by phone, caregivers, and patients primarily referenced how visitor restrictions hindered caregivers' efforts to collect information about the patients' well-being and advocate for them (Table 3). Information issues were exacerbated when patients were too ill to communicate themselves. Caregiver 2, whose husband was hospitalized for oncological surgery, described challenges to learning about her husband's well-being:

> So I dropped him off. And I'm thinking, "Ok, who is going to call me? Who is going to let me know?" I didn't go to work that day. I just wanted to be by my

phone, ready to hear someone...say he came out ok from the surgery, that they got everything, and that he's going to be ok. Well, scratch that. It did not end up that way...[the next] 48 hours were a blur because of the hoops I had to jump through to get a hold of somebody to try to talk to him and make sure he was ok.

Minimal caregiver-medical team communication further hindered caregivers' ability to advocate, already hampered by their lack of physical presence. As Caregiver 2 explained, she struggled to advocate, partly because she could not visually assess needs: "When you're there, you're the advocate...and you can see how your spouse is. I couldn't see him. I heard his voice, and that scared me so bad because I knew he wasn't making sense." Instead, she had to rely on medical staff to assess her husband's needs. The caregiver described how she had to call the nurses station numerous times before reaching someone to assess her husband. Other caregivers struggled

TABLE 3	Qualitative	themes	and	excer	pts
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Theme	Illustrative excerpts		
Impact of limited or no communication with the care team			
Advocacy challenges	It was a little difficult [not being present for patient's communication with medical team], because she's not always great at expressing how she's feeling. I just feel like being involved is more beneficial to her and to me. I'm less anxious if I know what's going onShe doesn't like to ask for help. Unless something is really wrong, she just says she's fine, and then you know that you need to press for more.		
	Caregiver 7, concerns about patient's ability to self-advocate		
Barriers to accessing information	There were times when he [patient] wasn't able to use the devices that are helpful for communication like phones and iPads. I just feel like I had to do a lot of the legwork for getting information. That would've nice to maybe have like a scheduled, you know, or somebody that was calling me to let me know what was going on.		
	Caregiver 5, challenges when patient too ill to communicate		
Impact of limited advocacy and information access			
Emotional distress	I don't think she was involved in any of the [care] decisions. She was just looking for somebody to tell her what was going on. She was totally isolated, and the longer isolation went on, the worse she got. And then she called me, and I'm half-groggy from drugs they're pumping into me, and the effects of that anesthesia. I think that scared her more than anything because I wasn't talking coherently.		
	Patient 2, caregiver's challenges learning patient's post-op status		
Poor care quality evaluations	I need to find out how I can get a hold of someone, because when he [patient] phoned me, nobody was with him Why didn't someone say, "You know what? He's not doing so well. He's still having the effects from the anesthesia"And a nurse had told me, "Call the hospital, tell them what room he's in, that you need to talk to the head nurse or whoever is doing his patient care, and tell them you want to be able to have them visually see and tell you what's going on." I said "OK." First of all, why should I have to do all of this?It's supposed to be the care of the doctor, the care of the hospital, their responsibility to get in touch with me. Something's not right.		
	Caregiver 2, challenges during emergent post-op situation		
Medical staff miscommunication about	t visitation		
Emotional distress	A social worker and a nurse came to the door to confront me about my not being willing to understand the visiting rules. And so I just looked at that particular social worker and I told her it was not me who was not understanding the rules, it was them that were changing it every time I turned aroundI never want to deal with nursing staff at that hospital ever again in my lifetime. I'd have to be dead to go to that hospital.		

Caregiver 1, confusion regarding visitation rules at end-of-life

because they were not physically present to communicate patients' needs or feelings. Caregiver 7, whose wife was hospitalized, explained his absence was "difficult because she's [patient] not always great at expressing how she's feeling...I just feel like being involved is more beneficial to her and to me. I'm less anxious if I know what's going on."

Downstream effects on emotional distress and perceived care quality

Most caregivers and patients described experiencing stress and lower satisfaction with care due to information and advocacy challenges created by limited communication with medical staff. Several patients keenly felt their caregiver's absence as an advocate because their illness severity hindered their communication. Patient 7 described her experience of being alone in the Emergency Department without her husband and unable to breathe as "horrible" and that the most frustrating aspect of her hospitalization was "lack of communication" with the medical team. Her breathing difficulties limited her ability to communicate well with both her husband and her medical team whereas, if her husband was present, "it would have been easier...I was extremely stressed, so I probably wasn't asking as many questions as I probably should have, where he probably could have."

Several caregivers and patients felt that the patient received worse care because of the visitation restrictions. As Patient 5, who was hospitalized for Leukemia treatment explained, he had some "bad days [when] I didn't eat...or was in pain" that could have been avoided if his wife was there, who "could have advocated for me if she saw me on those bad days where I couldn't really ask for pain meds or whatever, I don't know, or feed myself." While she was able to advocate for him by phone with the medical team, he believed that it was much less effective.

Impact on discharge counseling

Discharge counseling also suffered, further hindering caregivers' information access. All interviewed patients received written instructions at discharge, but only half of patients and two caregivers reported receiving counseling from medical team member at discharge. While patients felt that they were sufficiently instructed to handle their transition home, most caregivers had concerns about their level of knowledge to manage that transition. When asked whether the written instructions were sufficient, Caregiver 2 replied, "Yes and no," explaining that she did not have sufficient communication during restrictions, but that, due to discharge counseling from her husband's prior surgery before restrictions, she remembered how to care for him. This lack of information and opportunity to communicate worried caregivers. As Caregiver 4 explained, despite her years caregiving, discharge counseling still made her feel more confident about her abilities: I know that I could call my local doctor here or just take him [father] in, but there was something about that comfort with the nurse when you were leaving that made you feel when you were taking the patient that was still sick but recovering, "Ok, I can do this." And that's one thing your nurses at Maine Med do so well. They make you feel like you can handle it.

Similarly, caregivers felt that the structure of discharge did not facilitate opportunities to ask questions. As Caregiver 4 explained, when asked about whether she could speak to the nurse at discharge:

No. Somebody wheels him out in a wheelchair, with the paperwork on his lap, he comes out to the front door, you pulled up to the front door, they say, "Here you go," you say, "Thank you," and you get him in the car...He was very, very sick and could barely stand because of his weakness. I didn't ask any questions, I just needed to get him in the car.

Conflicting communications about visitations

Interviews also demonstrated communication issues not reflected in quantitative findings. Some participants reported distress around conflicting information regarding visitation. In one instance, a nurse told a caregiver that he could bring food to his wife, but he was turned away by staff at the hospital entrance. Another caregiver reported a significant conflict during her mother's care. While daytime staff gave her permission to visit her dying mother, the night nurse refused. Although the caregiver later received approval to visit at night, she did not due to fears of another altercation, and her mother passed away alone.

> I couldn't make myself walk by that nurses' station thinking, "I'm going to get yelled at, annoy people or [they'II] stare at me." So I didn't go back and my mother died alone, even though I told my family I was there. I wasn't and they don't know that. I told them I was there. And yeah, I never want to go back in that hospital. (Caregiver 1)

DISCUSSION

Our results suggest that visitation restrictions impacted communication between medical teams, caregivers, and patients. Compared to prerestrictions, caregivers were contacted less often by the medical team and more caregivers had *no* contact with the medical team. Like others, we also found poorer discharge communication, since fewer caregivers received discharge counseling.¹⁷ While some have found increased use of technologies like video conferencing, which can facilitate communication,¹⁶ we found little evidence that medical teams utilized these technologies. Our qualitative findings demonstrated that decreased communication with the medical team hindered caregivers' ability to assess patients' well-being and to advocate, often causing emotional distress and poor evaluations of care quality.

Our findings also highlight the potential negative consequences if caregivers receive conflicting information about visitation restrictions. Clear and consistent communication might avoid devastating incidents such as not being present at a patient's death. It is also uncertain whether the benefits of visitor restrictions outweigh the costs, given the unclear evidence that visitor restrictions decrease COVID-19 outbreaks.^{27,28}

Our findings may generalize to non-pandemic settings where distance hinders in-person access for caregivers. Complex care in rural states is frequently delivered in urban centers, requiring rural caregivers to travel long distances to visit their loved ones.²⁹ Efforts like the Caregiver Advise Record and Enable (CARE) Act require hospitals to involve caregivers (i.e., register caregivers in patients' EMR, inform caregivers of discharges/transfers, give caregivers discharge information and education). However, our study showcases experts' concerns that the CARE Act only goes so far without standardized processes and metrics for involving caregivers.³⁰ Quality improvement programs to facilitate communication between caregivers and medical teams with minimal burden to medical providers are also needed. These efforts should increase communication frequency between medical staff and caregivers and facilitate communication between patients and caregivers to help caregivers assess patient well-being and advocate for patients. This might include predictably scheduled contact with caregivers and/or increased utilization of video conferencing. These types of efforts may also be leveraged for those who cannot be physically present during a loved one's hospitalization.

Our study has limitations. Our data are drawn from a single health system in Maine, a rural state with limited racial and ethnic diversity, and thus our findings may not generalize to other regions. This may mean that communication frequency may be worse in other regions, since non-White patients and caregivers report lower quality and less frequent communication with providers.³¹⁻³³ It is also possible that medical teams had more contact with caregivers than was documented in the chart. However, our qualitative interviews suggest otherwise, since, except for one respondent, caregivers' reports of communication frequency reflected data abstracted from the patient's chart. On average, interviewed caregiver-patient dyads had more frequent documented communication episodes than dyads that were not interviewed. This may mean that, compared to our interviewees, most caregiver-patient dyads may have experienced more emotional distress related to lack of communication. Our qualitative sample was also small, and thus findings are exploratory. Anecdotal evidence suggests that some patients avoided medical care during the pandemic. Thus, hospitalized patients during visitor restrictions may have been sicker than those hospitalized prior to restrictions, which could have affected all outcomes of interest.

CONCLUSION

We found that hospital visitor restrictions were associated with significantly reduced frequency of communication between the medical team and caregivers. Hospitals should consider how to improve communication with remote caregivers. These strategies may be utilized to promote communication with rural and distance caregivers who cannot be physically present during a patient's hospitalization due to distance.

ACKNOWLEDGMENTS

This study was funded by a grant from the Northern New England Clinical and Translational Research Network.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ETHICS STATEMENT

The study protocol was approved by Maine Medical Center's Institutional Review Board (study id: 1590890). All interviewed participants provided verbal consent.

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REFERENCES

- Lund L, Ross L, Petersen MA, Groenvold M. Cancer caregiving tasks and consequences and their associations with caregiver status and the caregiver's relationship to the patient: a survey. *BMC Cancer*. 2014;14(1):1-13. doi:10.1186/1471-2407-14-541
- Isenberg SR, Aslakson RA, Dionne-Odom JN, et al. Family companions' involvement during pre-surgical consent visits for major cancer surgery and its relationship to visit communication and satisfaction. *Patient Educ Couns.* 2018;101(6):1066-1074. doi:10.1016/j.pec. 2018.01.011
- Shin DW, Cho J, Roter DL, et al. Preferences for and experiences of family involvement in cancer treatment decision-making: patientcaregiver dyads study. *Psychooncology*. 2013 22(11):2624-2631. doi:10.1002/pon.3339
- Tsuda K, Higuchi A, Yokoyama E, et al. Physician decision-making patterns and family presence: cross-sectional online survey study in Japan. Interact J Med Res. 2019 8(3):e12781. doi:10.2196/12781
- Epstein-Lubow G, Baier RR, Butterfield K, et al. Caregiver presence and patient completion of a transitional care intervention. Am J Manag Care. 2014;20(10):e349-e444.
- Hahn-Goldberg S, Jeffs L, Troup A, Kubba R, Okrainec K. "We are doing it together"; the integral role of caregivers in a patients' transition home from the medicine unit. *PLoS One.* 2018, 13(5):0197831. doi:10.1371/journal.pone.0197831
- Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulsky JA. Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. *Crit Care Med.* 2001;29(1):197-201. doi:10.1097/00003246-200101000-00040
- 8. Dionne-Odom JN, Ejem D, Wells R, et al. How family caregivers of persons with advanced cancer assist with upstream healthcare

decision-making: a qualitative study. *PLoS One*. 2019;14(3):1-15. doi:10.1371/journal.pone.0212967

- Litzelman K, Kent EE, Mollica M, Rowland JH. How does caregiver well-being relate to perceived quality of care in patients with cancer? Exploring associations and pathways. J Clin Oncol. 2016;34(29):3554-3561. doi:10.1200/JCO.2016.67.3434
- Harrison JD, Weiss R, Radhakrishnan NS, et al. A patient-centered environmental scan of inpatient visitor policies during the COVID-19 pandemic. J Patient Exp. 2021;8:23743735211049650. doi:10. 1177/23743735211049646
- Vincent A, Beck K, Becker C, et al. Psychological burden in patients with COVID-19 and their relatives 90 days after hospitalization: a prospective observational cohort study. J Psychosom Res. 2021;147:110526. doi:10.1016/j.jpsychores. 2021.110526
- Greenberg JA, Basapur S, Quinn TV, et al. Challenges faced by families of critically ill patients during the first wave of the COVID-19 pandemic. *Patient Educ Couns.* 2021;105:297-303. doi:10.1016/j.pec.2021.08.029
- Greenberg JA, Basapur S, Quinn TV, Bulger JL, Glover CM, Shah RC. Psychological symptoms among surrogates of critically ill patients during and before the COVID-19 pandemic. *Chest.* 2021;159(6): 2318-2320. doi:10.1016/j.chest.2020.12.056
- Creutzfeldt CJ, Schutz REC, Zahuranec DB, Lutz BJ, Curtis JR, Engelberg RA. Family presence for patients with severe acute brain injury and the influence of the COVID-19 pandemic. J Palliat Med. 2021;24(5):743-746. doi:10.1089/jpm.2020.0520
- Feder S, Smith D, Griffin H, et al. "Why Couldn't I Go in To See Him?" Bereaved families' perceptions of end-of-life communication during COVID-19. J Am Geriatr Soc. 2021;69(3):587-592. doi:10.1111/jgs. 16993
- Ersek M, Smith D, Griffin H, et al. End-of-life care in the time of COVID-19: communication matters more than ever. J Pain Symptom Manage. 2021;62(2):213-222. doi:10.1016/j.jpainsymman.2020. 12.024
- Zeh RD, Santry HP, Monsour C, et al. Impact of visitor restriction rules on the postoperative experience of COVID-19 negative patients undergoing surgery. Surgery. 2020;168(5):770-776. doi:10. 1016/j.surg.2020.08.010
- Creswell JW, Plano Clark VL, Gutmann ML, Hanson WE. Advanced mixed methods research designs.In: Tashakkori A, Teddlie C, eds., eds.Handbook of Mixed Methods in Social and Behavioral Research. Sage Publications; 2003:209-240.
- Division of Disease Surveillance. COVID-19: Maine Data–Coronavirus Disease 2019 (COVID-19)–Airborne Disease SurveillanceEpidemiology Program–MeCDC–Maine DHHS. 2022. Accessed April 8, 2022. https://www.maine.gov/dhhs/mecdc/infectious-disease/epi/ airborne/coronavirus/data.shtml
- 20. StataCorp. Stata Statistical Software: Release 17. StataCorp LLC; 2021.
- Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. A metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform. 2009;42(2):377-381.

- 22. Kripalani S, Jackson AT, Schnipper JL, Coleman EA. Promoting effective transitions of care at hospital discharge: a review of key issues for hospitalists. *J Hosp Med*. 2007;2(5):314-323.
- Edmonds KP, Ajayi TA. Do we know what we mean? An examination of the use of the phrase "Goals of Care" in the literature. *J Palliat Med*. 2019;22(12):1546-1552. doi:10.1089/jpm.2019.0059
- Fetters MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs-principles and practices. *Health Serv Res.* 2013;48(6 pt 2):2134-2156. doi:10.1111/1475-6773.12117
- Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77-101. doi:10.1191/1478088706qp063oa
- 26. MAXQDA 2020. VERBI Software; 2022.
- Frazer K, Mitchell L, Stokes D, Lacey E, Crowley E, Kelleher CC. A rapid systematic review of measures to protect older people in long-term care facilities from COVID-19. *BMJ Open*. 2021;11(10):e047012. doi:10. 1136/bmjopen-2020-047012
- Andrew MK, McNeil SA. COVID-19 outbreaks in acute and longterm care: conceptualizing patterns of vulnerability and benefits of interventions. *Lancet Reg Health Eur.* 2022;14:100312. doi:10.1016/ j.lanepe.2022.100312
- 29. Lam O, Broderick B, Toor S. How far Americans live from the closest hospital differs by community type. Pew Research Center. 2022. Accessed February 21, 2022. https://www.pewresearch.org/fact-tank/2018/12/12/how-far-americans-live-from-the-closest-hospital-differs-by-community-type/
- Applebaum AJ, Kent EE, Lichtenthal WG. Documentation of caregivers as a standard of care. J Clin Oncol. 2021;39(18): 1955-1958. doi:10.1200/JCO.21.00402
- Johnson RL, Roter D, Powe NR, Cooper LA. Patient race/ethnicity and quality of patient-physician communication during medical visits. *Am J Public Health*. 2004;94(12):2084-2090. doi:10.2105/AJPH.94.12.2084
- Cooper LA, Roter DL, Carson KA, et al. The associations of clinicians' implicit attitudes about race with medical visit communication and patient ratings of interpersonal care. Am J Public Health. 2012;102(5):979-987. doi:10.2105/AJPH.2011.300558
- Siminoff La, Graham GC, Gordon NH. Cancer communication patterns and the influence of patient characteristics: disparities in information-giving and affective behaviors. *Patient Educ Couns*. 2006;62(3):355-360.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Fenton A, Stevens S, Cost Z, et al. Patients' and caregivers' experiences of hospitalization under COVID-19 visitation restrictions. *J Hosp Med*. 2022;1-8. doi:10.1002/jhm.12924

8