American Journal of Hospice & Palliative Medicine®
2023, Vol. 0(0) 1–6

DOI: 10.1177/10499091231159522
journals.sagepub.com/home/ajh
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The Impact of Visitor Restrictions During COVID-19 Pandemic on Bereaved Family Members of Patients in Palliative Care Units

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Abstract

COVID-19 pandemic has impacted the families of patients in Palliative Care Units because of the visitor restrictions which were introduced to reduce the risk of infection. This study investigates how the bereaved families of the patients who died in end-of-life care during the pandemic evaluate the visitor restrictions and how the lack of direct communication with the patient affected them. We conducted a quantitative survey using an anonymous self-administered questionnaire. Participants were the bereaved families of patients who died in a Palliative Care Unit from April 2020 to March 2021. Their perspectives on the negative impact of COVID-19 pandemic on visitations, visitor restrictions, the quality of medical care in the month before the death of the patient, and online visitations were recorded in the survey. The results show that most participants experienced a negative impact on visitations. However, most respondents felt that the restrictions were unavoidable. According to visitor permissions in patients' last days, bereaved families were satisfied with the medical care provided for the patient and the amount of time spent with the patient in his/her last days. The importance of direct meetings during the last days of the patients' life for their family members was presented. We suggest further research to find measures which enable visitation in palliative care units, as caregiving from family and friends and maintaining COVID safety regulations are equally significant in end-of-life care.

Keywords

visit restrictions, breaved family members, end of life care, palliative care units, covid-19 pandemic, negative impact

Introduction

The coronavirus disease 2019 (COVID-19) pandemic has significantly transformed the quality of medical care.[1] It has remarkably impacted the visitors of inpatients.[2] Visitors were prescribed a restricted visit approach since visits increased the risk of infection.[3,4] However, direct communication between patients and their families is essential for the palliative care unit (PCU) that is responsible for end-of-life care.[5,6] In some countries, PCUs completely prohibit visits.[7] Guidelines also recommend different visiting conditions according to the condition of infections.[8,9] Few studies have investigated the effect of restricted visits on bereaved families in end-of-life care.[10,11]

Objective

In this study, we surveyed bereaved families, investigating how they evaluate visitor restrictions during the pandemic and how the lack of direct communication with the patient affected them. We investigated how direct connection between the patient and family, which is important in palliative care, could be maintained following restrictions on contact for infection prevention.

Methods

A survey was conducted using an anonymous self-administered questionnaire. Participants were the bereaved families of patients who died in PCU from April 2020 to March 2021. Out of the 157 patients who died in the PCU, family members of 145 patients were selected as participants, excluding 12 patients with no bereaved families or family could not be contacted. The hospital staff sent them an anonymous questionnaire with response envelopes 3 months after the death of the patient.

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Visitor Restrictions

Considering the requirements in end-of-life care and infection control, the PCU differentiated the conditions for visitations at three levels according to the patient's expected prognosis of death. Level 1; prognosis expected in more than 1 month, visitations were prohibited. Level 2; prognosis expected within 1 month, visitations of 30 minutes with two people per session were permitted. Level 3; prognosis expected within few days, one registered caregiver could constantly accompany the patient. The prognosis prediction was determined by the attending physician using the palliative prognostic index.[12] There were 3 steps taken as basic infection prevention measures, all visitors underwent temperature checking at the hospital entrance (37.5°C or less), their hands were disinfected with alcohol before entering the hospital ward, and they wore masks during their stay in ward. There were no regulations regarding the age of the visitors and their relationship with the patient.

Measures

Theme 1. Negative Impact Factors due to Covid-19 Pandemic

We asked about negative impacts of COVID-19 pandemic in the PCU context as "Were there any negative impact due to COVID-19?" Respondents answered this question by choosing multiple answers among the 8 items provided. They were "outpatient consultation," "timing of hospitalization," "hospitalization duration," "visitations," "going out/staying out overnight," "treatment content," "no negative impact," and "others."

Theme 2. Opinions on Visitor Restrictions

Opinions on visitor restrictions during the hospitalization period comprised 5 items as follows: "visitor restrictions are unavoidable and necessary for infection control," "I am concerned about infection risks during visitations," "I want the visitor restrictions to be gradually relaxed according to the situation," "visitor restrictions are unnecessary if the visitor ensures infection prevention," and "there is no need for visitor restrictions in a palliative care unit."

Theme 3. The Quality of Medical Care in the Month Before the Death of the Patient

The quality of medical care in the month before the death of the patient was examined. Theme 3 comprises three domains[1]: "medical staff had taken sufficient infection countermeasures,"[2] "I was allowed to visit according to the patient's condition," and[3] "I was able to accompany the patient for sufficient time before he/she died." The survey was conducted using a 6-point scale which comprised "completely agree," "agree," "somewhat agree," "somewhat disagree," "disagree," and "completely disagree."

Theme 4. Online Visitations

Respondents indicated whether online visitations were conducted with the patients during the hospitalization period. We surveyed the reasons why the participants did not partake in online visits; the response options were the following 7 items: "I do not know how to do it," "I do not have a tablet or smartphone," "I am not accustomed to talking online," "it is meaningless if I do not meet in person," "I have no experience with it," "the patient did not wish to do so," and "others."

Data Analysis and Ethical Issues

Quantitative data were analyzed using descriptive statistics and SPSS (v. 28). Participation in this study was voluntary and the participants were allowed to withdraw consent even after participation. Participants were assured of anonymity and confidentiality. This study was conducted with the approval of the research ethics committee of Kyoto Min-iren Asukai Hospital.

Results

Ninety-seven people among the 145 target participants responded to the survey. Out of them, 15 requested not to participate this study, 82 consenting respondents were recruited. Sample characteristics are reported in Table 1. The

Table 1. Characteristics of the Respondents.

	n	%
Gender		
Female	64	78.0
Male	15	18.3
Unknown	3	3.7
Relationship to the deceased		
Son/daughter	32	39.0
Husband/wife/partner	30	36.6
Brother/sister	8	9.8
Parent	1	1.2
Others	5	6.1
Unknown	6	7.3
Age (years)		
≤39	1	1.2
40-49	14	17.1
50-59	13	15.9
60-69	22	26.8
70-79	22	26.8
≥80	9	11.0
Unknown	1	1.0

relationships between the family members and the deceased patient were as follows: children, 32; spouse, 30; sibling, 8; parent, 1; other, 5; and unknown, 6.

Theme 1. Negative Impact Factors due to Covid-19 Pandemic

Table 2 shows the factors that had a negative impact due to COVID-19 pandemic. More than half of the respondents (49, 59.8%) experienced a negative impact on visitations. The second highest factor was no negative impact (25, 30.5%). Other aspects that were negatively impacted included "Outpatients/staying out overnight" (7, 8.5%), "Outpatient visits" (3, 3.7%), "Hospitalization duration" (2, 2.4%), "Hospitalization timing" (1, 1.2%), and "Treatment content" (1, 1.2%).

Theme 2. Opinions on Visit Restrictions

Most respondents felt that the restrictions were unavoidable (55, 67.1%) (Table 3). One-third of the respondents stated "I want the restrictions to be gradually relaxed" (25, 30.5%). Other responses included "Visitor restrictions are unnecessary in the PCU" (11.0%), "I am concerned about infection risks" (9.8%), and "Restrictions are unnecessary under basic infection measures" (6.1%).

Table 3 shows the multiple regression analysis evaluating the association between negative impact (independent variable) and opinions on visit restrictions (dependent variable). The group that agreed that there was a negative impact on visitations had a statistically higher number of responses indicating "Visit restrictions are unavoidable" (P=.028). The respondents who mentioned a negative impact on treatment felt that "Restrictions are unnecessary under basic infection measures" ($P < .001$).

Table 2. Opinions on Visitor Restrictions.

	n	%
Were There Any Negative Impact due to COVID-19?		
Visitations	49	59.8
Going out/staying out overnight	7	8.5
Outpatient consultation	3	3.7
Hospitalization duration	2	2.4
Timing of hospitalization	1	1.2
Treatment content	1	1.2
Others	1	1.2
No negative impact	25	30.5
How do you feel about visitor restrictions during the hospitalization period?		
Visitator restrictions are unavoidable given infection control	55	67.1
I Want the visitor restrictions to be gradually relaxed according to the situation	25	30.5
I Am concerned about infection risks during visitations	8	9.8
There is no need for visitor restriction in a palliative care unit	8	9.8
Visitor restriction is unnecessary if the visitor ensures infection prevention	5	6.1

Table 3. Partial Regression Coefficient.

	Unavoidable			Gradually Relaxed		Infection Risks		Unnecessary in the PCU		Unnecessary under the Basic Infection Measures		
Negative impact	β	SE		β	SE	β	SE	β	SE	β	SE	
Visitations	.415	.185	*	.135	.177	−.092	.118	.098	.122	.048	.089	
Goint out/staying out overnight	−.118	.212		.401	.202	.233	.135	.086	.14	−.047	.102	
Outpatient consultation	.329	.349		−.559	.333	.34	.222	−.148	.231	−.028	.168	
Hospitalization period	.477	.345		.209	.329	−.09	.22	−.056	.228	−.027	.166	
Timing of hospitalization	.27	.476		−.359	.454	−.044	.303	−.105	.314	−.051	.229	
Treatment content	.059	.585		−.201	.558	−.616	.372	−.043	.386	1.023	.282	**
Other	.27	.476		.641	.454	−.044	.303	−.105	.314	−.051	.229	
No negative impact	.285	.196		−.064	.187	−.016	.124	.113	.129	.077	.094	

β: Partial regression coefficient SE: Standard error.
*$P < .05$; **$P < .01$.

Theme 3. The Quality of Medical Care in the Month Before the Death of the Patient

Table 4 shows the quality of medical care in the month before the death of the patient. There was no bereaved family member who selected "somewhat disagree," "disagree," or "completely disagree." More than half of the respondents agreed completely to "medical staff had taken sufficient infection countermeasures" and "I was able to visit according to the patient's condition." Most respondents felt strongly that they could accompany the patient for sufficient time before they died.

Theme 4. Online Visitations

There were three individuals who conducted online visitations, 75 who did not, and four who did not respond. Table 5 shows the reasons for the 75 people who did not do so. The most common reason was "other," with the response of "I was able to visit." There were 17 who had no experience of online visitations, and 15 who said that the patient did not wish to do so.

Discussion

Direct communication in the PCU became difficult due to COVID-19 pandemic. It is reported that the isolation and depression of the family are increasing by visit restrictions.[13]

Table 4. The Quality of Medical Care in the Month Before the Death of the Patient.

	n	%
Medical staff had taken sufficient infection countermeasures		
Completely agree	42	51.2
Agree	33	40.2
Somewhat agree	4	4.9
Somewhat disagree	0	.0
Disagree	0	.0
Completely disagree	0	.0
Unknown	3	3.7
I was allowed to visit according to the patient's condition		
Completely agree	45	54.9
Agree	32	39.0
Somewhat agree	2	2.4
Somewhat disagree	0	.0
Disagree	0	.0
Completely disagree	0	.0
Unknown	3	3.7
I was able to accompany the patient before they died		
Completely agree	50	61.0
Agree	22	26.8
Somewhat agree	8	9.8
Somewhat disagree	0	.0
Disagree	0	.0
Completely disagree	0	.0
Unknown	2	2.4

In this study, we surveyed how bereaved family members evaluated visit restrictions. Most bereaved family members acknowledged its negative impact on visitations. Some stated that the negative impact did not fall under any of the given items. The frequencies of the item "Visitor restrictions are unavoidable" was high in the group that said that there was a negative impact on visitations. They understood the social situation and accepted the inevitability of restrictions. We observed an accepting attitude toward restrictions among the participants.

For the question regarding the quality of medical care in the month before the death of the patient, more than half of the respondents did "completely agree," to "Medical staff had taken sufficient infection countermeasures" and "I was able to visit according to the patient's condition." Besides, 60% of the participants answered "completely agree" that they were able to spend enough time with the patient. Surprisingly, there were no negative answers for these three questions. The bereaved family members maintained the satisfaction that they were able to spend the end-of-life together with the patient even during the pandemic.

Direct communication between the patient and family is primary in end-of-life family care.[14] The inability of family members to visit during the last few days of a patient's life affects his/her mental preparation for death, hinders emotional support, and causes severe distress.[10] Therefore, visitation for the purpose of saying goodbye is extremely important for individualized care.[15-17] A survey of bereaved families in Japan reported that over 90% of family members wished to be present at the time of the patient's death.[18] Direct visitations at the last few days of the patient's life are important and meaningful for the bereaved families.

In Spite of online visitations are provided in our PCU, among the bereaved family members, only three responded that they had conducted online visitation. There were two explanations provided for the item "others," which was the most common reason selected for not conducting online

Table 5. Online Visitations.

	n	%
Did you have online visitations with the patient during the hospitalization period?		
Yes	3	3.7
No	73	89.0
Missing	6	7.3
Reasons for not having online visitations		
I have no experience with online visitations.	17	20.7
The patient did not wish to have visitations.	15	18.3
I do not know how to do it.	11	13.4
It is meaningless if we do not meet in person.	11	13.4
I do not have a tablet or smartphone.	8	9.8
I am not accustomed to talking online.	7	8.5
Others	20	24.4

visitations. The first was "I was able to visit directly" and the second was "the patient's state was poor and we could not talk to them." The average duration of hospital stays for patients who died was 23 days, with the prognosis of death predicted to be in units of weeks from the time of hospitalization. Therefore, there were many patients in poor condition who verbal communication was unavailable. As direct visitations were allowed (albeit with conditions), there were few opportunities for conducting online visitations, thereby reducing its frequency. However, some responses were "I do not know how to do it" and "I am not accustomed to it." The medical staff were also not familiar with online visitations, and information about the online visitation procedure was insufficient. Due to its effectiveness and importance, online visitations were deemed an alternative method when in-person visitations were difficult.[19-21] Online visitations stabilized the patient's mind and influenced the satisfaction of the bereaved family members.[22] Similar to bedside manner, verbal and nonverbal website manner skills is essential during online visits.[23] Anticipating an increased frequency of imposing visitor restrictions due to the COVID-19 pandemic, medical professionals must be educated to become skilled in online visitations even at the end-of-life care.

Limitations

There are several limitations to this study. First, the participants were bereaved family members from a single medical institution, and the small sample size may have resulted in limited responses. Second, as the decision to respond to the survey was the bereaved family members' choice, responses were not received from all bereaved family members. The bias of the opinions of non-respondents was not reflected in this study and should be considered. Third, the validity of the survey questions used in this study was not verified.

Conclusions

The spread of the COVID-19 pandemic resulted in the imposing of visit restrictions in the PCU. Bereaved family members experienced a negative impact on visitations. On the other hand, they deemed to spend enough time with the patient before their death even during the pandemic. They felt that the restrictions were unavoidable and understood the need for such visit restrictions. It is recommended that considerations be made to enable direct visitations during the last few days of the patient's life while taking infection countermeasures in the future.

Acknowledgments

The authors thank the patients and families for their cooperation in this study.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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References

1. Kerlin MP, Costa DK, Davis BS, Admon AJ, Vranas KC, Kahn JM. Actions taken by US hospitals to prepare for increased demand for intensive care during the first wave of COVID-19: a national survey. *Chest*. 2021;160:519-528.
2. Hart JL, Turnbull AE, Oppenheim IM, Courtright KR. Family-centered care during the COVID-19 era. *J Pain Symptom Manag*. 2020;60:93-97.
3. Parodi SM, Liu VX. From containment to mitigation of COVID-19 in the US. *JAMA*. 2020;323:1441-1442.
4. Hick JL, Hanfling D, Wynia MK, Pavia AT. Duty to plan: health care, crisis standards of care, and novel coronavirus SARS-CoV-2. *NAM Perspect*. 2020;2020:10.
5. Teno JM, Clarridge B, Casey V, Edgman-Levitan S, Fowler J. Validation of toolkit after-death bereaved family member interview. *J Pain Symptom Manag*. 2001;22:752-758.
6. Casarett D, Shreve S, Luhrs C, et al. Measuring families' perceptions of care across a health care system: preliminary experience with the Family Assessment of Treatment at End of Life Short form (FATE-S). *J Pain Symptom Manag*. 2010;40:801-809.
7. Jaswaney R, Davis A, Cadigan RJ, et al. Hospital policies during COVID-19: an analysis of visitor restrictions. *J Publ Health Manag Pract*. 2022;28:299-306.
8. Jones-Bonofiglio K, Nortjé N, Webster L, Garros D. A practical approach to hospital visitation during a pandemic: responding with compassion to unjustified restrictions. *Am J Crit Care*. 2021;30:302-311.
9. Hart J, Summer A, Yadav KN, et al. Content and communication of inpatient family visitation policies during the COVID-19 pandemic: sequential mixed methods study. *J Med Internet Res*. 2021;23:e28897.
10. Mayland CR, Hughes R, Lane S, et al. Are public health measures and individualised care compatible in the face of a pandemic? a national observational study of bereaved relatives' experiences during the COVID-19 pandemic. *Palliat Med*. 2021;35:1480-1491.
11. Matsuda Y, Takebayashi Y, Nakajima S, Ito M. Managing grief of bereaved families during the COVID-19 pandemic in Japan. *Front Psychiatr*. 2021;12:637237.
12. Morita T, Tsunoda J, Inoue S, Chihara S. The Palliative Prognostic Index: a scoring system for survival prediction of

terminally ill cancer patients. *Support Care Cancer*. 1999;7: 128-133.
13. Strang P, Bergström J, Martinsson L, Lundstrom S. Dying from COVID-19: loneliness, end-of-life discussions, and support for patients and their families in nursing homes and hospitals. A national register study. *J Pain Symptom Manag*. 2020;60:2-13.
14. Anhang Price R, Stucky B, Parast L, et al. Development of valid and reliable measures of patient and family experiences of hospice care for public reporting. *J Palliat Med*. 2018;21:924-932.
15. Hanna JR, Rapa E, Dalton LJ, et al. A qualitative study of bereaved relatives' end of life experiences during the COVID-19 pandemic. *Palliat Med*. 2021;35:843-851.
16. Schloesser K, Simon ST, Pauli B, et al. "Saying goodbye all alone with no close support was difficult"- Dying during the COVID-19 pandemic: an online survey among bereaved relatives about end-of-life care for patients with or without SARS-CoV2 infection. *BMC Health Serv Res*. 2021;21:998.
17. Witkamp FE, van Zuylen L, Borsboom G, van der Rijt CCD, van der Heide A. Dying in the hospital: what happens and what matters, according to bereaved relatives. *J Pain Symptom Manag*. 2015;49:203-213.
18. Otani H, Yoshida S, Morita T, et al. Meaningful communication before death, but not present at the time of death itself, is associated with better outcomes on measures of depression and complicated grief among bereaved family members of cancer patients. *J Pain Symptom Manag*. 2017;54:273-279.
19. 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;69:587-592.
20. deLima Thomas J, Leiter RE, Abrahm JL, et al. Development of a palliative care toolkit for the COVID-19 pandemic. *J Pain Symptom Manag*. 2020;60:22-25.
21. Kuntz JG, Kavalieratos D, Esper GJ, et al. Feasibility and acceptability of inpatient palliative care E-family meetings during COVID-19 pandemic. *J Pain Symptom Manag*. 2020; 60:28-32.
22. 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 Manag*. 2021;62:213-222.e2.
23. Chua IS, Jackson V, Kamdar M. Website manner during the COVID-19 pandemic: maintaining human connection during virtual visits. *J Palliat Med*. 2020;23:1507-1509.