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Running Title: Family-Centered Care during COVID19

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Family support is more, not less, important during crisis. However, during the COVID-19 pandemic, maintaining public safety necessitates restricting the physical presence of families for hospitalized patients. In response, health systems must rapidly adapt family-centric procedures and tools to circumvent restrictions on physical presence. Strategies for maintaining family integrity must acknowledge clinicians' limited time and attention to devote to learning new skills. Internet-based solutions can facilitate the routine, predictable, and structured communication which is central to family-centered care. But the reliance on technology may compromise patient privacy and exacerbate racial, socioeconomic, and geographic disparities for populations that lack access to reliable internet access, devices or technological literacy. We provide a toolbox of strategies for supporting family-centered inpatient care during physical distancing responsive to the current clinical climate. Innovations in the implementation of family involvement during hospitalizations may lead to long-term progress in the delivery of family-centered care.

Introduction

Family-centered care is threatened during the COVID-19 pandemic. The participation of family members in a manner that allows families, patients, and the healthcare team to collaborate is the core of family-centered care. Strategies for delivering family-centered care typically include open family presence at the bedside;³ regular, structured communication with family members; and multidisciplinary support. These prepare family members for decision-making and caregiving roles,¹ with the goal of reducing family members' experiences of anxiety, depression, and post-traumatic stress following hospitalization.¹ Family-centered care is desired by patients and families, may improve their outcomes, and may also reduce burnout and moral distress among clinicians.¹

Large-scale disasters intensify stressors and basic human needs to feel safe, connected, calm, useful, and hopeful.² Yet, infectious diseases outbreaks make proximity dangerous.³ Physical, or social, distancing is the principal mitigation strategy used to reduce transmission in the COVID-19 pandemic,⁴ with a profound impact on the delivery of family-centered inpatient care. Health systems must severely restrict or eliminate family presence for all patients, to protect the health of patients, family members, and workers.⁵

Restrictions on family presence should not undermine adherence to the principles of family-centered care. Defining patients' goals of care is a priority during the pandemic and typically necessitates family engagement.⁶ Therefore, it is essential to rapidly adapt family-centric procedures and tools to circumvent restrictions on physical presence. We present a framework for family-centered care in the context of COVID-19 and provide a toolbox of strategies to implement in the inpatient setting.

Goals of family-centered care in the COVID-19 pandemic

The goals of family-centered care during physical distancing remain the same and are focused on facilitating (1) respect for the role of family members as care partners, (2) collaboration between family members and the healthcare team, and (3) maintenance of family integrity.³ The pandemic necessitates that efforts to meet these goals adapt to a rapidly changing clinical culture. Family-centered care has primarily relied on family members' physical presence at the bedside to promote trust, communication, involvement in caretaking, and shared decision-making.¹ The term "visitation" is replaced by "family presence" in the family-centered care

paradigm. During the COVID-19 pandemic, family presence must be supported in non-physical ways to achieve the goals of family-centered care.

In this pandemic, as in prior infectious outbreaks, governments, health systems, and individual clinicians change their typical practices to focus on public health rather than individuals' outcomes.¹³ Clinicians may also be performing unfamiliar duties, including learning new clinical procedures and providing care in novel spaces with newly formed teams. Family-centered care strategies in this context must acknowledge the changed ethical perspective and clinicians' limited time, attention, and effort to devote to learning and assimilation.

Ethical considerations

Strategies to support family presence during physical distancing rely heavily on existing patient or family smartphones and computers, stable internet access, and technological literacy. These strategies are likely to cause differential access to family-centered care. In the United States, where a majority of the population reports use of the internet or a smartphone, there are wide racial and socioeconomic disparities in access to computers and broadband internet. Older Americans are less likely than younger groups to use the internet regularly.⁷ Fewer than two-thirds of homes in rural areas of the United States report home broadband internet connection.⁸ Urban areas face similar areas of internet inequality along socioeconomic lines.⁹ Therefore, use of technology-heavy family-centered care strategies requires assessing individual families' access to these resources and devising ways to overcome these potential barriers to avoid worsening existing health disparities.

Despite the need for physical distancing, permitting limited family presence at the bedside may be necessary for the protection and safety of the patient or to maintain family integrity. For example, physical family presence should be supported when possible for pediatric patients, laboring or post-partum patients, and people with severe neurocognitive disability or who are nearing the end of life. Exceptions allowing for physical presence should be clearly defined and communicated to clinicians, families and patients. Exceptions should be adjudicated in a transparent and equitable manner, preferably through a centralized system, to avoid discrimination in family access and additional strain on the clinical team.¹⁰ These processes should also aim to decrease the bedside clinical team's moral distress and "avoid conflicts of commitments," aligned with the recommended practices for resource allocation decisions.¹¹

The United States is permitting use of technologies that may not be fully compliant with the Health Insurance Portability and Accountability Act Privacy, Security, and Breach Notification Rules (HIPAA Rules) during the COVID-19 public health emergency.¹² This enables communication and provision of telehealth through existing commercial platforms. Clinicians using technologies that do not follow HIPAA Rules should disclose to patients and families that they may compromise patient privacy. Use of HIPAA Rules-compliant platforms and security features on all platforms should be prioritized to protect patient privacy.

Strategies for delivery family-centered inpatient care

The delivery of family-centered care begins at entry to the health system. The patient and family should receive an explanation of any restrictive policies that limit the physical presence of family members. As families often have limited face-to-face contact at the point of entry, a public-facing website should provide additional information. The explanation of the policy should include rationale and use language and tone that seeks to defuse and avoid conflict. The public-facing material should also empower patients and families to anticipate and prepare for next steps.¹³ The website should also link to community resources, free or low-cost public internet programs, and information about the health system's preferred communication platforms. Finally, hospitals should provide a mechanism for delivery of essential items to the patient, such as glasses, phone chargers, and advance directives.

Inpatient clinical teams should establish a communication plan with the patient and family members shortly after admission or transfer within the hospital. These transitions are times of uncertainty for the patient and family member.¹⁴ The clinical team should contact the family members directly, with the patient's permission when applicable. The clinical team should aim to (1) establish a primary family contact designated by the patient, who is ideally but not necessarily the patient's legal healthcare decision maker; (2) document the technologies available to the patient and family for communication; and (3) identify and mitigate any barriers to communication and engagement (**Table 1**). Together, they should plan for future clinical updates and the communication platform they will use. The clinical team should provide asynchronous activities for the family to do, such as compiling questions and journaling, to maximize communication efficiency and coping.

Structured, predictable communication with families should occur daily unless otherwise requested, using strategies outlined in **Table 2**. Two essential modes of contact are between (1) the family and the patient and (2) the family and the clinical team. Videoconferencing is preferable to telephone calls, and improves emotional connection through facial expressions and non-verbal communication.¹⁵

Minimizing training and documentation burdens on clinical staff is paramount during pandemic care. Comprehensive education around telehealth and communication with distanced family members is not feasible. Instead, health systems should provide clinical staff with easily accessible communication guides and documentation tools. Build templated notes with scripted conversation guides for key communication topics in the electronic health record and promote serious illness communication strategies that have been tailored to COVID-19.¹⁶ Examples of templated notes are available on the Palliative and Advanced Illness Research Center website.¹³

Delivery of family-centered care may require reinterpreting or reinventing roles within the multidisciplinary team as clinical staff become a scarce resource. Medical, nursing, or social work students removed from clinical rotations may be able to provide skilled support while advancing their own education and skills.¹⁷ Students can virtually visit families and patients to promote coping strategies, coordinate engagement efforts, and streamline communication with the clinical team.¹³ Additionally, the health system should leverage partnerships with community organizations to collaboratively assist family members. Proactive outreach to community partners about policies limiting family presence may alleviate health system stress as the need for supportive care increases.¹³ For example, local faith leaders may be equipped to provide virtual pastoral care support.

Strategies for delivery of family-centered care near the end of life

Separation near the end of a patient's life is particularly tragic. Conduct conversations explaining transition to comfort-focused care via multi-user videoconferencing, including multiple distanced family members, translators, and longitudinal clinicians as appropriate. When possible allow physical presence, even if very limited, and maximize family presence using strategies in **Table 2**. Involve supportive care teams for the patient and family, including palliative care, pastoral care, and behavioral health, recognizing that these service lines are also likely to experience strain.

Conclusions

Family-centered care is more, not less, important during a pandemic. Physical distancing requires nimble adaptation of standard practices. Innovative approaches that involve family members in inpatient care during the COVID-19 pandemic may lead to long-lasting progress in, rather than regression from, the standards of family-centered care the healthcare community has recently achieved.

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Table 1. Barriers to family communication and potential mitigation strategies.

<i>Barrier</i>	<i>Mitigation</i>
Family spokesperson or healthcare proxy unavailable during daytime hours	Utilize night and weekend coverage to continue seamless family communication
Family members without internet access or device capable of videoconferencing	Engage using telephone and teleconferencing Provide a hospital-issued phone with free outgoing calls to patients, including pre-paid calling cards as needed Provide the family with resources for low-cost or free internet programs, if available Describe visual scene, care provided, and patient behavior in more detail to family
Patient without device capable of videoconferencing	Provide patients with access to videoconferencing via a hospital-owned device (e.g., equip a workstation on wheels with a camera and videoconferencing platform software or use tablets) Encourage and facilitate family delivery of device to the hospital for patient use, if available
Family members do not speak the same primary language as clinical team	Access translation services during video- or teleconferencing
Family members or patient have limited technological literacy	Provide instructions for use of the preferred videoconferencing platform tailored to all technological literacy levels Teach the use of the preferred platform for videoconferencing Engage using telephone and teleconferencing
Patient lacks communication aids such as glasses or hearing aids	Facilitate delivery of essential items from the family to the patient

Table 2. Strategies for communication with and engagement of families during physical distancing

<i>Domain of family-centered care</i>	<i>Strategies</i>
Engagement of families with patients: synchronous communication	<p>Encourage patient and family to call, text, and videoconference with one another using their preferred methods as often as desired</p> <p>Facilitate delivery of communication devices, including charging equipment, from the family to the patient</p> <p>Provide free internet access to inpatients and assist them in connecting their personal devices</p> <p>Use speakerphone to facilitate communication from family members to the patient even if the patient is not able to communicate*</p>
Engagement of families with patients: asynchronous communication	<p>Help the patient record and send audio, video, or written messages to their family members</p> <p>Encourage the patient to journal about family memories and feelings during the hospitalization</p> <p>Use videoconferencing, including using hospital-owned devices through windows or doors for patients on isolation, to show family members their loved one and the environment*</p> <p>Read, print out, or play messages from the patient's family to the patient*</p> <p>Request pastoral care support for prayer as desired, or facilitate patient's external faith leader prayers or services via videoconferencing*</p>
Engagement of families with patients: environment	<p>Create a system to have limited personal effects delivered to patients' room such as children's art, sports memorabilia, or religious items (reinforce that nothing of monetary value should be delivered and that it may be difficult to return items to the family)*</p> <p>Customize the patient's environment after learning favorite food, music, audiobooks,</p>

	<p>and television preferences from family members*</p> <p>Describe the patient's environment to family members, including the presence of items sent from the family*</p>
<p>Communication between clinical team and family</p>	<p>Contact family at the time of transfer or admission to establish primary contact, legal healthcare decision maker, and communication plan</p> <p>Define and document the plan for family contact, including the responsible clinical team member, on a daily basis</p> <p>Daily videoconferencing (or telephone contact) with a primary family contact as standard unless otherwise requested</p> <p>Document daily communication for transparency, accountability, and consistency</p> <p>Attempt to include families in rounds as possible, but recognize that this may be infeasible under clinical strain</p> <p>Clearly communicate and reiterate the role of the clinical team member contacting the family, including when obtaining consent</p> <p>Promote consistency in who contacts family members when possible (e.g., primary clinical team member participates when consultants discuss care with family members)</p> <p>Ask family members to describe the patient's past times and life story, including important people in their life, to facilitate conversation between the clinical team and the patient</p>

*Strategies to emphasize in patients who are unable to communicate due to their clinical condition

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