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A Commentary of The National Catholic Bioethics Center on Health Care and the Life Sciences

Also in this issue: "The Gift of the Apostolic Pardon," by Marie Hilliard

Why Family Is Critical to the Care of the Sick

Annmarie Hosie, RN, Michael Vacca, and Ashley Fernandes, MD

The coronavirus pandemic is bringing new and great losses, challenges, and change in our lives, relationships, and social interactions. Amid these, health care institutions, especially hospitals and nursing homes, are extraordinarily tasked with meeting the needs and safety of so many people sick and dying from COVID-19, along with those of their families, the staff, and the public.

One clear and immediate responsibility of health care institutions is to limit contagion. Many infection control strategies have been rapidly reemphasized or introduced, including universal precautions, screening, hand hygiene stations, personal protective equipment (PPE), contained areas and teams, physical distancing, increased cleaning, instructional signage, training, telehealth, reduced nonurgent services, and free parking. These strategies may place an economic and organizational burden on already stretched institutions, but they pose few other risks to persons.

In contrast, the practice adopted by some health care institutions of extreme visitation restrictions, and in some settings banning family completely,[1] poses clearly foreseeable risks to those who are sick, their family, the staff, and society. These risks include destabilization of trust between these institutions and the communities they serve, sick people's avoidance of hospitals for fear of dying alone, and grave harm to the nature of persons through the marginalization of the intrinsic familial aspect of their being.[2] Other anticipated harms are widespread suffering, guilt, grief, and recrimination lasting long past the time of crisis.

To honor, maintain, and advocate for family connection during the coronavirus pandemic, we briefly outline why family is critical to caring for the sick.

The Family Is a Universal and Fundamental Human Good

That the family is a fundamental good, and the basic building block of society, is recognized by right reason and human rights charters.[3] Human beings across cultures, times, and faiths have natural bonds with family that are essential for our flourishing. The family, as Pope St. John Paul II wrote, is "a path common to all, yet one which is particular, unique and unrepeatable, just as every individual is unrepeatable; it is a path from which man cannot withdraw."[4]

The family teaches us how to be human and helps us fulfill the deepest reason for our life, which is to give and receive love.[5] The loving and instructive companionship of family and the cohesiveness of society that ensues from such companionship are also essential to the common good. The right that flows from the intrinsic and extrinsic good of family is the freedom to enjoy the love, support, care, and protection that its members offer each other. Importantly (and thankfully), the imperfections and limitations that exist in every family do not negate its fundamental goodness or our right to experience it.

The Role of Health Care Institutions Is to Heal the Sick and to Support (Not Supplant) the Family

Evaluating the legitimacy of any law or policy affecting families must begin with considering the fundamental goodness of the family and our rights in relation to it. While health care institutions do have a duty to preserve human life, this duty is fulfilled in relation to the nature of the human person and to our vocation to love.[6] The fundamental goods that are part of human nature and the objective moral order include the family of a person—who is a union of soul, mind, and body, not just a physical flesh-and-blood being—oriented to communion with others. In short, being in relationship with others is the essence of what it means to be human.[7] However well-meaning the efforts, to strive at all costs to preserve life without recognizing what it means to be a human person in its fullest sense is profoundly unjust. Everyone has a basic, prepolitical human right to the companionship of one's family because this companionship expresses the nature of persons oriented to interrelationships of love and solidarity. This right can never be violated by anyone, least of all those charged with the work of healing.

In an institution, the sick person is automatically placed—by virtue of the need to be healed or palliated—in a vulnerable position vis-à-vis the health care professional, who has specialized knowledge and technical skills.[8] This power is granted by society so that the institution may meet its proper end, which is healing of the person (not of society per se). Hence, while health care institutions and those who work in them have immense power, they do not have the absolute power to exclude fundamental goods nor to redefine their powers according to society's current needs or expectations. To do such would violate subsidiarity by displacing the proper autonomy of the family and improperly expanding institutional power.

Total exclusion of family members from loved ones in a time of critical illness or dying represents the triumph of a profoundly

impersonal individualism. This individualism threatens to displace authentic community with a collection of isolated individuals who lack the bonds of love, solidarity, and concern for one another, causing all to lose sight of the common good. To isolate the sick person for the betterment of that person and of others as a public health measure is one good, to be sure; but that person also exists as an anthropological subject within a *communio personarum*—a community of persons. Sick people can be isolated to help them to be well, but they cannot be isolated from themselves—selves that always exists in relation to others. John Paul II makes this clear in *Gratissimam sane* when he notes that the difference between individualism and personalism is the gift of self to others.[9]

Family Presence Enables Health Care Professionals to Recognize and Fulfill Their Proper Role

The primary role of health care professions has always been to promote healing by careful attention to four goods: the person's biomedical good, autonomy, fullest being (or flourishing), and spiritual good.[10] However, institutional exclusion of family presence seems to place the biomedical good over all others—including the sick person's autonomy, need to flourish (even *in extremis*), and spiritual good. At first glance, preserving biological human life as the highest priority seems unassailably positive; we do not downplay the good of preserving life when we can. But it is the life of a person (not a body), in all his or her aspects—physical and metaphysical—that is worthy of preserving.

Family involvement during institutional care helps health care professionals to better see the person, contextualize his or her current circumstances, and intervene in the best possible way for that person in those circumstances. Family frequently help in many practical ways, such as assisting their loved one to eat and drink, use the toilet, wash, and be orientated, comfortable, and safe through conversation, observance, and prayer. Family attention to these essential aspects of care can reduce the preventable harms that so often occur during illness and institutionalization, and this attention helps professional caregivers to ensure that all of the person's needs are being met.

Family presence also helps to moderate the inherent power imbalance between health professionals and patients, ultimately protecting both. A sign of current ambivalence in this relationship is the understandable but potentially misleading hero status being ascribed to health care professionals "on the front line." The *hero* title, while recognizing the risks and the daily sacrifices, may suggest an infallible person clothed with immense power. Yet history tells us that, in the aftermath of this crisis, we will see evidence of human beings at their best and at their worst in times of great duress. Many indeed—in health care, families, and other areas—are working extremely hard to care for more seriously ill people in extraordinarily challenging circumstances, and the only true heroes among us are those who model themselves after the One who called himself a servant (Mark 10:45). Health care institutions that support family presence therefore also help those working within them to remain within the safe and healthy boundary of humble service.

The covenantal (not contractual) relationship between health professionals and patients requires sacrifice for the good of the person in need. Does including family at the bedside of the seriously ill person involve an increased (albeit marginal) risk to the health professional or to society? Perhaps. But what are the risks if such a fundamental need is not granted? The risks are destabilization of the sacred trust within these covenantal relationships, others' avoidance of institutions for fear of dying alone, and potentially grave harm to the nature of the person by marginalizing the relational element of personhood.[11]

Evidence Supports the Critical Role of Family Care During Sickness

Research reveals that family care of members during sickness and disability is customary and undervalued. In 2015 almost one in five Americans (43.5 million people) reported they provided informal care to an adult relative, for an average of 24.4 hours a week even though many experienced consequent physical, emotional, and financial strain that was underrecognized by health professionals.[12] In Australia, with a population less than one tenth that of the United States, the monetary value of unpaid care (i.e., what it would cost to provide professional care) is an estimated A$60.3 billion (or US$41.9 billion) annually.[13] This family care is given in all settings.

Recent literature has sought to understand long-term restrictions on visitation in acute and critical care settings,[14] reporting barriers that include attitudes, team practices, workloads, and systems that are not oriented toward patient- and family-centered care.[15] Fears of increased infection, litigation, and burden on health care professionals and other patients are also factors, although largely unrealized.[16] In contrast, people who have experienced critical illness say that family helped them obtain information; feel understood, safe, and valued; and regain strength, willpower, and hope.[17] In a study of more than fifteen thousand patients in the intensive care unit, an evidence-based bundle that included family partnership as a core component resulted in lower likelihood of hospital death within seven days and of next-day mechanical ventilation, coma, delirium, physical restraint use, ICU readmission, and discharge to a facility other than home.[18] In a study in an acute care setting for older people, open visiting created a positive culture that improved trust and communication between families and health care professionals.[19] This small snapshot of evidence highlights the tangible benefits of family presence during institutional care, which are likely to remain even in a pandemic and should be weighed, like any other therapy, against potential risks.

For these reasons, willingness to allow and facilitate prudent family visitation is essential in the COVID-19 pandemic, lest some of the current overreach reset the norm for future crises. In suggesting prudent visitation, we obviously exclude circumstances in which family members' visits are limited because of lack of PPE or because of a need to ensure the safety of those immediately attending in acute incidents (but these have been rare). Along with appropriate precautions and the consent of the person receiving care, health care professionals and institutions should consider fundamental human goods, including the mystery of the transcendent and metaphysical elements of each person, and realize that the family cannot be sterilely extracted from the calculus of what is in the best interests of the person or of society. This need remains important even though not all who become sick will have family or will want them present, and even though not all family will be able or willing to attend. Meeting this need is also possible, having been safely achieved in institutions that have committed to ensure that sick and dying people are not left alone and totally

isolated from family. These efforts require wisdom, patience, and charity on all sides to achieve reasonable accommodations. These may not be ideal compared with ordinary circumstances, but they will help to avoid extreme reactions and risks that would almost certainly prove detrimental on one side or the other.

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The Gift of the Apostolic Pardon

Marie Hilliard, RN

During the COVID-19 pandemic, there are challenges in meeting the right of the faithful to receive the sacraments. This right is circumscribed by specific conditions, including that sacraments be available at the appropriate time. The faithful are hungry for the sacraments, and there is great evidence that clergy are also suffering from their inability to provide them. They are seeking alternative ways and sites to deliver them validly and safely.

There also is the tremendous need to minister to the families of the victims of the pandemic. Required social isolation prevents families' access to loved ones at the point of greatest need, when there is the danger of death. This is compounded by the reality that clergy may not have direct access to the dying or even to their family members. Thankfully, technology enables the ministry to families to continue even if through less-than-ideal means.

However, the lack of direct sacramental access, especially to the dying, continues. One great possibility is the Apostolic Penitentiary's suggestion that priests collaborate with local health authorities to serve as "'extraordinary hospital chaplains' … in compliance with the norms of protection from contagion, to guarantee the necessary spiritual assistance to the sick and dying."[1]

Apostolic Pardon and Plenary Indulgence

An indulgence is the partial or plenary (total) remission of temporal punishment for sins already forgiven under certain conditions defined by the Church. All baptized members of the Christian faithful who are in communion with the Church and in the state of grace may receive an indulgence. To gain a plenary indulgence, the person must have at least the general intention of acquiring it and must fulfill the three specific conditions: sacramental confession, Eucharistic communion, and prayer according to the Holy Father's intentions.[2]

A great gift of the Church is the apostolic pardon, a special plenary indulgence offered when death is imminent. The *Manual of Indulgences* states the following:

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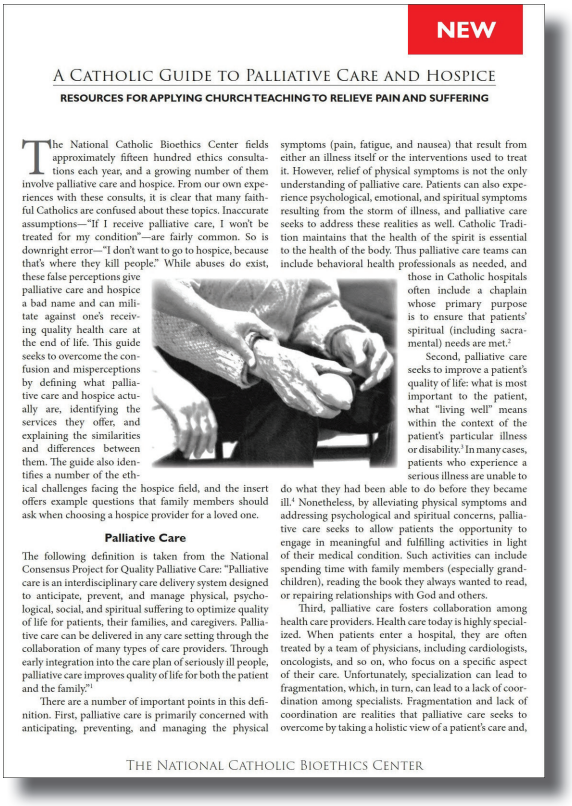
A New Guide from the NCBC

A Catholic Guide to Palliative Care and Hospice

This brief but clear guide seeks to overcome confusion about palliative care and hospice by defining what each one actually is, identifying the services each offers, and explaining the similarities and differences between them. The guide also identifies ethical challenges facing the hospice field.



NEW

A Catholic Guide to Palliative Care and Hospice

RESOURCES FOR APPLYING CHURCH TEACHING TO RELIEVE PAIN AND SUFFERING

The National Catholic Bioethics Center fields approximately fifteen hundred ethics consultations each year, and a growing number of them involve palliative care and hospice. From our own experiences with these consults, it is clear that many faithful Catholics are confused about these topics. Inaccurate assumptions—"If I receive palliative care, I won't be treated for my condition"—are fairly common. So is downright error—"I don't want to go to hospice, because that's where they kill people." While abuses do exist, these false perceptions give palliative care and hospice a bad name and can militate against one's receiving quality health care at the end of life. This guide seeks to overcome the confusion and misperceptions by defining what palliative care and hospice actually are, identifying the services they offer, and explaining the similarities and differences between them. The guide also identifies a number of the ethical challenges facing the hospice field, and the insert offers example questions that family members should ask when choosing a hospice provider for a loved one.

Palliative Care

The following definition is taken from the National Consensus Project for Quality Palliative Care: "Palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families, and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care providers. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family."[1]

There are a number of important points in this definition. First, palliative care is primarily concerned with anticipating, preventing, and managing the physical symptoms (pain, fatigue, and nausea) that result from either an illness itself or the interventions used to treat it. However, relief of physical symptoms is not the only understanding of palliative care. Patients can also experience psychological, emotional, and spiritual symptoms resulting from the storm of illness, and palliative care seeks to address these realities as well. Catholic Tradition maintains that the health of the spirit is essential to the health of the body. Thus palliative care teams can include behavioral health professionals as needed, and those in Catholic hospitals often include a chaplain whose primary purpose is to ensure that patients' spiritual (including sacramental) needs are met.[2]

Second, palliative care seeks to improve a patient's quality of life: what is most important to the patient, what "living well" means within the context of the patient's particular illness or disability.[3] In many cases, patients who experience a serious illness are unable to do what they had been able to do before they became ill.[4] Nonetheless, by alleviating physical symptoms and addressing psychological and spiritual concerns, palliative care seeks to allow patients the opportunity to engage in meaningful and fulfilling activities in light of their medical condition. Such activities can include spending time with family members (especially grandchildren), reading the book they always wanted to read, or repairing relationships with God and others.

Third, palliative care fosters collaboration among health care providers. Health care today is highly specialized. When patients enter a hospital, they are often treated by a team of physicians, including cardiologists, oncologists, and so on, who focus on a specific aspect of their care. Unfortunately, specialization can lead to fragmentation, which, in turn, can lead to a lack of coordination among specialists. Fragmentation and lack of coordination are realities that palliative care seeks to overcome by taking a holistic view of a patient's care and,

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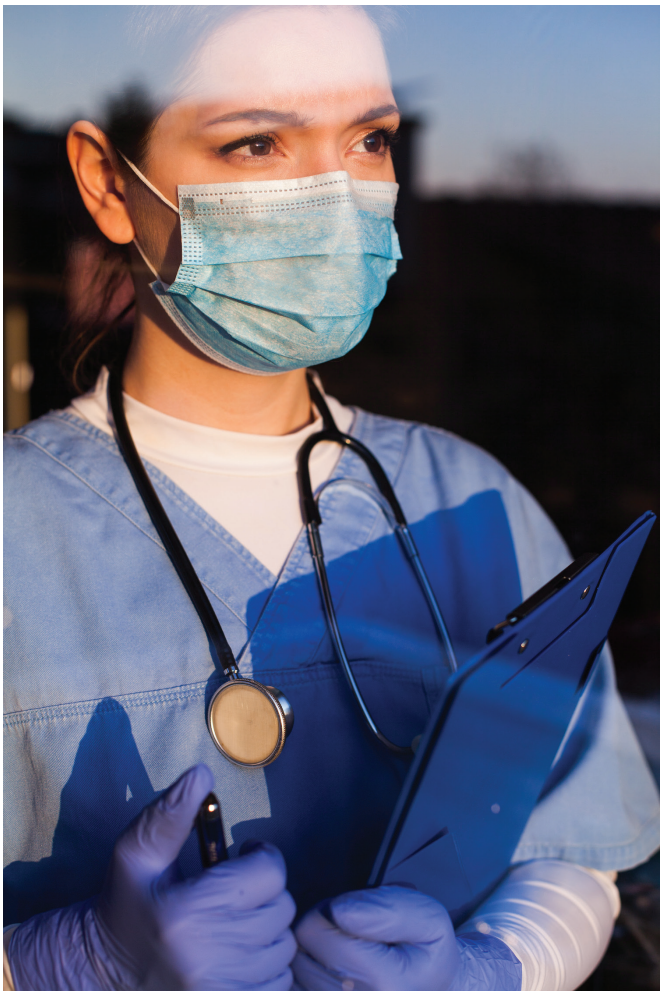

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> A priest who administers the sacraments to someone in danger of death should not fail to impart the apostolic blessing to which a *plenary indulgence* is attached.
>
> If a priest is unavailable, Holy Mother Church benevolently grants to the Christian faithful, who are duly disposed, a *plenary indulgence* to be acquired at the point of death, provided they have been in the habit of reciting some prayers during their lifetime; in such a case, the Church supplies for the three conditions ordinarily required for a plenary indulgence.[3]

The apostolic pardon is usually administered to a conscious or unconscious patient after the sacrament of Anointing of the Sick. It requires no direct contact with the recipient. Therefore, the diocesan bishop could consider approving the administration of the apostolic pardon after the administration of individual absolution, after the Rite for Emergencies when integral confession or Anointing of the Sick are impossible, or when general absolution is administered (even using a bullhorn).[4] The advantage of the Anointing of the Sick over the Rite for Emergencies is that the priest does not need to receive an external sign of contrition required for absolution, for example, with an unconscious patient. In such a situation and when Anointing of the Sick is impossible, conditional absolution could be imparted.

The apostolic pardon is imparted with the following words. (If the person is able, the response is *Amen*.)

> Through the holy mysteries of our redemption, may almighty God release you from all punishments in this life and in the life to come. May he open to you the gates of paradise and welcome you to everlasting joy.
>
> or
>
> By the authority which the Apostolic See has given me, I grant you a full pardon and the remission of all your sins in the name of the Father, and of the Son, and of the Holy Spirit.

A number of persons engaged in health care ministry, as well as the patients and families they serve, may be unaware of the apostolic pardon. At the time of impending death, and in the absence of a priest, the family or health care worker should help the patient to pray for such an indulgence, even if it is unclear whether the patient is conscious enough to do so. Again our generous Church grants this plenary indulgence to persons who are properly disposed and who have been in the habit of reciting some prayers during their lifetime as a substitute for the three usual conditions.

A recent decree by the Apostolic Penitentiary on the granting of a plenary indulgence to the faithful in the current pandemic expands on this further. The gift of special indulgences is granted to the faithful suffering from COVID-19 and their family members as well as to health care workers who in any capacity care for them if through mass, the rosary, the stations of the cross, or some other devotional or prayer, they "[offer] this trial in a spirit of faith in God and charity towards their brothers and sisters, with the will to fulfil the usual conditions … as soon as possible."[5]

Even those who pray for the end of the epidemic, relief for those who are afflicted, and eternal salvation for those who have died have access to the plenary indulgence under the same conditions if they "offer a visit to the Blessed Sacrament, or Eucharistic adoration, or reading the Holy Scriptures for at least half an hour, or the recitation of the Holy Rosary, or the pious exercise of the Way of the Cross, or the recitation of the Chaplet of Divine Mercy."[6]

Interestingly, when addressing the situation in which death is imminent and there is no access to the Anointing of the Sick or viaticum, the Apostolic Penitentiary states that the substitute for the three usual conditions for the plenary indulgence is having "recited a few prayers during their lifetime," while "the use of the crucifix or cross is recommended."[7] This demonstrates the pastoral care of the Church.

Importance of the Sacraments

If there is a message to be received during this pandemic, it is the importance of the sacraments, not just because of their salvific nature but also for the graces imparted by them. But access to grace abounds. Just praying for those affected by the pandemic, and fulfilling the related conditions, can effect a plenary indulgence. Currently despite the suffering faced by the human race, there is a great opportunity to access the graces available to all who seek them.

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