Patient Isolation during Infectious Disease Outbreaks: Arguments for Physical Family Presence

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This article argues that outbreak preparedness and response should implement a ‘family presence’ policy for infected patients in isolation that includes the option of physical visits and care within the isolation facility under some conditions. While such a ‘physical family presence’ (PFP) policy could increase infections during an outbreak and may raise moral dilemmas, we argue that it is ethically justified based on the least infringement principle and the need to minimize the harms and burdens of isolation as a restrictive measure. Categorical prohibition of PFP during the course of an outbreak or epidemic is likely to result in unnecessary harms to patients and families, and violate values such as the moral commitments of families to care for each other. Supporting the option of PFP under particular circumstances, on the other hand, will least infringe these moral considerations. An additional reason for a family presence policy is that it may facilitate voluntary cooperation with isolation and other restrictive measures. We provide an analysis of these considerations for supporting modes of family presence during an outbreak emergency, before defending the riskier option of PFP in the isolation facility from plausible objections and concerns.

Introduction

Outbreaks of novel, emerging or re-emerging infectious diseases with high morbidity or mortality rates pose significant threats to human lives and security that demand strict public health responses. In the absence of effective vaccines or treatments, responses to recent outbreaks of diseases such as severe acute respiratory syndrome (SARS), Middle East Respiratory Syndrome (MERS) and Ebola virus disease (EVD) typically included isolation of infected or symptomatic patients as a strategy to break the chain of transmission from infected to healthy individuals and limit the spread of the disease.

The experience of being isolated in a healthcare facility, plus the prospect of succumbing to illness and dying alone in a ward, is one that often involves unenviable fear and suffering for both patients and their loved ones. During the 2003 SARS outbreak in Singapore for example, SARS patients were not allowed to receive visitors even if it were their final moments, and families of patients who died from SARS were not allowed to perform last rites or see the patients’ bodies (Pang, 2013). Frontline workers also had to live with the fear and uncertainty of dying in such a way (Tai, 2006).

Isolation of individuals as transmission sources has long been a staple measure in outbreak and emergency response. However, its moral territory and practice warrant closer scrutiny for two reasons. First, harsh isolation policies may lead to behaviors which undermine the public health goals of limiting disease spread and minimization of mortality and morbidity during an outbreak. Second, such policies may impose serious psychological adverse effects on patients, families and healthcare providers (Chung et al., 2005; Maunder et al., 2003; Mak et al., 2009; Gardner and Moalley, 2015). The real lived fears and burdens of these stakeholders should be recognized and prompt a consideration of better protection of their interests and welfare.
Specifically, a ‘family presence’ policy should be implemented to support isolation regimens during outbreak emergencies to alleviate some of the greater burdens of isolation on patients, including those who require treatment for a critical health issue in a hospital that treats infected patients and who are then similarly confined to prevent spread. In the broadest sense, ‘family presence’ means allowing individuals who stand in familial relations to patients to be ‘there’ for or with the patients. (By ‘familial relations’, we mean existing intimate relations that need not be formed through genetic or formal associations such as marriage.) In the context of isolated patients, a family presence policy may be defined as an approach for patient care in which familial others are allowed to express or provide care for these patients, through modes of physical visits and care and e-communication.

The recent World Health Organization (WHO)’s document ‘Guidance on managing ethical issues in infectious disease outbreaks’ (World Health Organization, 2016) sets out the need for communication channels between confined patients and families to mitigate their psychosocial burdens, while the recent position statement (part 2) of the Society of Critical Care Medicine on the ethics of outbreaks endorses ‘e-presence’ or e-communication to support family-centered care (Papadimos et al., 2018), which may be broadly defined as optimization of care that is planned around and experienced by a family as a unit of care (Kuo et al., 2012). E-communication should not be an ethically controversial mode of family presence, although its implementation in certain settings may be hindered by infrastructural or resource barriers.

Physical family presence (PFP) in the form of face-to-face contact may, however, be opposed on the ground of protecting public health and security, which includes protection of family members from harm. Nevertheless, PFP had been implemented to some extent during the 2013–2016 West African EVD epidemic (Grady, 2017) and the ongoing epidemic in the Democratic Republic of Congo. For example, modular isolation treatment units (described more below) were created and installed near communities affected by EVD that allow families to see EVD patients from the outside (Devi, 2018). Whether PFP should be allowed when the isolation units or wards are within hospitals or dedicated treatment facilities is unclear, given restrictive visitation policies during outbreak emergencies. To date, there is little ethical analysis of whether and when PFP at the bedside within the isolation facility itself should be allowed during an outbreak emergency.

This article argues that outbreak preparedness and response should implement a family presence policy for patients in medical isolation, which includes the option of PFP within the isolation facility under some conditions. While such a PFP policy could increase infections during an outbreak and may raise moral dilemmas, we argue that it is ethically justified based on the need to minimize the harms and burdens of isolation as a public health measure, and the least restrictive or least infringement principle (Kass, 2001; Upshur, 2002). As a core ethical principle in public health, the least infringement principle requires choosing the public health intervention that is the least infringing of general moral considerations, provided that efficacy in achieving the public health goal is not greatly reduced. Categorical prohibition of PFP during the course of an outbreak or epidemic is likely to result in unnecessary harms to patients and families, and violate values such as the moral commitments of families to care for each other. Supporting the option of PFP under particular circumstances, on the other hand, will least infringe these moral considerations. An additional reason is that PFP may facilitate voluntary cooperation with isolation and other restrictive measures. We provide an analysis of these considerations for supporting PFP and other modes of family presence during an outbreak emergency, before defending the riskier option of PFP in the isolation facility from plausible objections and concerns.

Promoting Voluntary Cooperation with Restrictive Measures

Restriction of movement is a strategy dating back several centuries, and practices include what Elbe (2012) called the ‘ban’—forbidding the infected from being in a given society permanently (e.g. leper’s exile). With advances in scientific understanding of infectious diseases and biomedical strategies for prevention and control, the necessity of the ban to protect a community is less warranted and thus less used. Practices like social distancing, quarantine and isolation allow the sick (and potentially sick) to remain within their community by placing temporary limits on their physical interaction with the healthy. This similarity notwithstanding, isolation can be much more burdensome for individuals compared to the other measures (Giubilini et al., 2018). For highly communicable and dangerous infectious diseases, infected patients would likely be placed in strict isolation in a healthcare facility in which they are largely deprived of personal comforts and physical contact with others. Public health authorities typically possess wide powers to restrict
individual freedoms, and although the processes and outcomes of isolation and other restrictive measures may sometimes be non-transparent or unclear, policymakers and the public usually accept their use to protect the wider community against the risks of transmission and associated harms such as mortality and morbidity (Gostin et al., 2016).

However, authorities need to exercise caution in implementing these measures. The WHO document ‘Guidance for managing ethical issues in infectious disease outbreaks’ states

...that the effectiveness of these measures should not be assumed; in fact, under some epidemiological circumstances, they may contribute little or nothing to outbreak control efforts, and may even be counterproductive if they engender a backlash that leads to resistance to other control measures (World Health Organization, 2016: 25).

This article argues that outbreak preparedness and response should implement a ‘family presence’ policy for infected patients in isolation that includes the option of physical visits and care within the isolation facility under some conditions. While such a ‘physical family presence’ policy could increase infections during an outbreak and may raise moral dilemmas, we argue that it is ethically justified based on the least infringement principle and the need to minimize the harms and burdens of isolation as a public health measure. Categorical prohibition of PFP during the course of an outbreak or epidemic is likely to result in unnecessary harms to patients and families, and violate values such as the moral commitments of families to care for each other. Supporting the option of PFP under particular circumstances, on the other hand, will least infringe these moral considerations. An additional reason for a family presence policy is that it may facilitate voluntary cooperation with isolation and other restrictive measures. We provide an analysis of these considerations for supporting modes of family presence during an outbreak emergency, before defending the riskier option of PFP in the isolation facility from plausible objections and concerns.

To mitigate fears and related behaviors and conflicts, changes to restrictive measures during past and present outbreak emergencies have been made to enable people to be with their loved ones. Notably, during the West African EVD epidemic, the practice of burning or burying EVD victims without any family involvement to prevent spread was changed in response to violent resistance and non-reporting of deaths (Coltart et al., 2017). WHO (2017) now promulgates that burials of EVD victims should proceed only with family agreement, with funeral rites and biosafety procedures modified to protect the living. And when EVD broke out in the Democratic Republic of Congo in 2017, ‘proper’ isolation centers—treatment tents with windows that allow families to see patients—were set up as a ‘response to past outbreaks in which people sometimes shunned sealed-up isolation units into which patients seemed to disappear’ (Grady, 2017). More recently, the Chambre d’Urgence Biosécurisée pour Épidémies (CUBE)—a modular and reusable biosafety level 4 emergency unit with transparent plastic sheets—was developed and implemented by a humanitarian group in northeastern Congo. The CUBE means physical confinement and segregation but not social disconnection as it allows relatives to visit, see and speak to patients behind the safety of the sheets (Devi, 2018; Maliro, 2018).

One may argue that the recent EVD epidemics in Africa are special cases requiring a PFP approach due to the specific infrastructural, social, cultural and political context: the low level of trust in the government and in foreign humanitarian assistance with the outbreak response, and lack of familiarity with the medical and public health interventions which led to widespread fear in the public. Thus the above changes and allowances may be said to be pragmatic deviations from traditional implementation of restrictive measures, in view of an understanding that prohibition of family presence may undermine containment efforts. Yet ethics—the importance of protecting individual rights and interests during public health emergencies—also drives and justifies these changes. The modified burial practices for example aim to preserve the dignity of the deceased and enable relatives to fulfill their ‘religious and personal rights to show respect for the dead’ (World Health Organization, 2017). In favor of safe and dignified burials, the head of the emergency EVD operations in Congo with the International Federation of Red Cross and Red Crescent Societies said: ‘Community acceptance—that’s our security’ (Associated Press, 2018).

Care Ethics, Human Security, and Trust

The last statement suggests a rethink of security notions and practices during public health emergencies. In contemporary public health discourse, conceptions of security—health security, national security, human security, etc.—have become prominent in deliberations on outbreak emergency response (Heymann, 2003; Aldis, 2008; Enemark and Selgelid, 2012a). The goal of advancing security, whatever adjective is used, is to put
in measures to deal with real or perceived threats and reduce the probability of damage to values such as ‘physical safety, economic welfare, autonomy, psychological well-being. . ’ (Baldwin, 1997: 13).

It is important, however, to consider how public health securitization practices like restrictive measures may themselves pose a threat to important values such as community ties and relational values. As Robinson (2011) argues, human security should be guided by an ethics of care. As a normative ethical theory, an ethics of care (or care ethics) promotes the recognition that what matters to people is not mere survival as independent autonomous persons. What also matters to people as relational creatures is being cared for and caring for significant others (Held, 2006). Based on an ethics of care, Robinson argues that focusing security solely on ‘care-free’ (read: without anxiety, worry, or fear) existences might obscure how for many people, their sense of security (or insecurity) depends significantly on the extent to which they are supported in fulfilling their responsibilities and care for particular others (Robinson, 2011: 7). ‘When these relations of care are damaged or severed, security is threatened’ (Robinson, 2011: 10).

Our interest here is not to defend Robinson’s conceptualization of human security, which seeks to counter political and social structures of exclusion and domination that do not recognize care as a component of security and long-term flourishing. Suffice to say, we see her broadening of security as compatible with our case for the public health relevance of supporting modes of family presence during outbreak emergencies. Providing security to people by supporting PFP and other modes of family presence may contribute to rates of responsible reporting of suspected cases and voluntary seeking of treatment, and more broadly the fostering of trust between State and citizenry in facing an infectious disease threat. Trust means depending on others—the authorities in this case—to safeguard what we care about, while applying discretionary powers. Placing trust is often an automatic and unconscious act which only becomes conscious when doubt in the trustee appears (Baier, 1986). An outbreak emergency is exactly the time where public trust in the authorities is of utmost importance on the one hand, but where it may be fragile on the other (Blair et al., 2017). Support for family presence options would securitize care to particular others for whom we take responsibility, and consequently, increase public trust in the authorities and promote public health.

Certainly, these effects would come not only from the possibility of PFP and other family presence options but also through effective public communication. An effectively communicated family presence policy should mitigate individual fears related to separation, opaque treatment of vulnerable loved ones and the possibility of not seeing them again.

**Harm and Burden Minimization**

The detrimental effects of medical isolation on patients are well-documented and emphasis has been made to improve the quality of care for this group of patients. A literature review on its psychological effects shows that isolation, even as a routine hospital measure, can be a frightening and anxious affair for patients, given that ‘[i]solation is the preferred state for very few species, and indeed for humans it is anathema’ (Gammon, 1999: 17). Against a backdrop of hospital lock-downs and heightened fear, evidence from past outbreaks demonstrates the profound and devastating impact of isolation measures on patients, their families and healthcare workers. A study with a Toronto-based hospital’s core medical team and mental health care providers during the 2002–2003 SARS outbreak found that isolated SARS patients experienced feelings of ‘fear, loneliness, boredom, and anger’ (Maunder et al., 2003: 1250) while family members ‘found it difficult that they could not provide direct support to their sick relative by visiting’ (1248). Similar observations were made by healthcare workers who took care of SARS patients in Hong Kong (Chung et al., 2005). The stress and stigma of being a SARS patient, or being involved in their care, contributed by the enforcement of isolation, have led some to call SARS a mental health catastrophe (Mak et al., 2009). While many survivors, including healthcare workers who became patients themselves, were resilient enough to deal with these effects, many also suffered long-lasting psychological damage in the form of post-traumatic stress disorder and depression after the epidemic (Mak et al., 2009; Gardner and Moallef, 2015).

The serious adverse effects of isolation appear to be far more keenly felt in the cases of children, as suggested by healthcare workers involved in their care during the SARS epidemic (Koller et al., 2006). Some were observed to change from being highly distressed to states in which they were non-communicative and detached from any interest in other people. In view of the children’s distress and behavioral changes, healthcare workers sought to act as a ‘substitute family’ for these children (Koller et al., 2005: 55). The extent to which they could fill in for parents or other loved ones in terms of mitigating the children’s distress and other psychological harms through their care is unclear. Writing on the tragedies of family members who died separated from one another...
in a Sierra Leone Ebola treatment center during the 2013–2016 outbreak, Lappia and Carrick (2017: e2) noted that efforts at intimate care provided by staff could not provide comfort for the loneliness of the children and their desire to be with their parents; ‘one of the greatest difficulties of all… was the terrible obstacles to comforting the young victims as they were torn from their families… separated from the intimate human contact that had been a constant in their life’s experience, an unshakeable basis of family culture in Sierra Leone’.

Minimizing the burdens of isolated patients to protect the community of which they are a part of should be an essential component of outbreak or epidemic management. Thus, the WHO document ‘Guidance for managing ethical issues in infectious disease outbreaks’ states that restrictive measures ‘should be backed up with sufficient resources to ensure that those subject to the restrictions do not experience undue burdens’ (26). These resources include ‘the means to communicate with loved ones and the outside world. Fulfilling these needs is essential to respect individual dignity and address the significant psychosocial burden of confinement on individuals and their loved ones’ (World Health Organization, 2016: 26).

In our understanding, this guidance is specifically pointing at e-communication support, which has been implemented in past outbreaks in some settings to minimize patient burdens. Phone connection, for example, was a key communication resource between patients and relatives during the SARS outbreak in Canada (Koller et al., 2006). As an isolated patient in Ontario writes: ‘the importance of connection to significant others by phone… is especially important, given that the hospital system, especially when under the stress of an epidemic, becomes more hierarchical and less human…’ (McNamee, 2004). However, it is important to support the option of PFP within the isolation facility itself. The CUBE was built as ‘as definitely a step towards humanising patient care’: ‘the patients are with their families. That makes a big difference. That supports their lives’ (Devi, 2018: 2428). The physical presence and care of loved ones are thus essential to prevent or minimize severe harms for at least some patients, such as young children given the serious and possibly long-term psychological harm they may suffer if deprived of parental presence as mentioned above.

Another group of patients for whom PFP could be essential or critical to minimize harms and protect their welfare would be those who are expected to die soon. One way to construe this is to see it as coterminous with family-centered care at the end of life. Ridenour and Cahill (2015: 107) write that ‘the human reality of death brings with it basic human needs, threats of suffering, and moral responsibilities that are shared across traditions and that require a communal response of “accompanying” the dying’. Drawing on this claim, Dugdale (2015: 183) argues that one component of a good death is a strong sense of community as ‘it clarifies our sense of self, upholds us in our weakness, and facilitates the achievement of an art of dying well’. While the presence of the medical team and other members of society (e.g. fellow religious members) could contribute to a sense of community and a good death, ‘most dying patients share the messiness of death with only a select few’ (Dugdale, 2015: 184). Other than easing their separation anxieties, fears and distress, PFP could empower the isolated individual in the eyes of relatives, such that a loved one’s final moments are laid in dignity and peace or, for those estranged, redeemed in ‘saving grace’ and reconciliation. It would also minimize regret and help with grief and closure should the patient be lost. PFP as such would confer significant benefits on patients and their families.

In the next section, we respond to possible objections against PFP within isolation facilities.

**Concerns with PFP**

One likely major concern with PFP is that it may (significantly) undermine public health objectives. The custom of families providing care at the bedside was rightfully suspended during South Korea’s 2015 MERS outbreak as it was a significant contributory factor to community spread (World Health Organization, 2015). Understandably, PFP that is normally allowed in healthcare systems during ‘peace times’ would need to be disrupted in an emergency context. We agree that an overly liberal approach to PFP—one where relatives could choose whenever and, however, they want to be with infected patients—would likely undermine outbreak control and overwhelm a public health infrastructure during an outbreak emergency.

Family presence for isolated patients, as defended here, is a set of options that lie on a spectrum of risk of transmission, with e-communication on one end (very low risk) and care involvement in the isolation unit on the other end (high risk). A family presence policy—what mode(s) to allow and support—should take into account epidemiological factors pertaining to the infectious disease (e.g. mode and ease of transmission, start and length of contagiousness, and morbidity and mortality rates); pharmacological intervention factors (e.g.
availability and effectiveness of vaccines, diagnostic availability and difficulty, and effectiveness and complexity of treatment); the scale of the outbreak; the risks and benefits of physical presence options; the availability of other options; and resources to implement them. Low-resource settings may be lacking in information and communication technology infrastructure, and thus may not be able to rely on e-presence in lieu of physical presence; the latter could be facilitated by risk-reduction technologies such as the CUBE (the overall production cost of which is cheaper than standard Ebola treatment units (Devi 2018)). On the other hand, high resource settings could provide easy and free access to e-communication and develop protocols to permit PFP based on the above factors.

Besides these factors, another consideration for whether to permit PFP in the isolation unit is whether such presence is feasible and useful. To minimize risk of infection, family members should don personal protection equipment (PPE) as used by frontline healthcare workers. The required PPE may be a hazmat suit (as worn by frontline workers treating EVD patients during the 2013–2016 West African outbreak), which is too physically demanding even for experienced professionals to endure for long. In addition, protective masks inhibit effective communication—facial expressions would be hidden—and would under certain conditions quickly lose its protective filtration function due to sweat and bodily moisture. Due to the limitations of PPE, PFP in the isolation unit for care purpose might need to be limited to a short while, which may tip the balance against allowing PFP due to heightened risks and lack of utility. Nevertheless, PFP need not be long for some purposes (e.g. last goodbye for dying patients), and prolonged presence can be feasible and useful. During a presentation on an early draft of this article on 8 March 2017, an infectious disease control specialist shared that during the 2009 influenza A (H1N1) pandemic, while there was then considerable scientific uncertainty about the virulence of the disease, the mother of a symptomatic toddler in Singapore was allowed to stay with the child in the isolation unit. The reason for doing so was because of anticipated challenges with caring for such a young child, but as we argue here, such allowance should be grounded in moral considerations such as harm and burden minimization.

Still, healthcare workers may oppose PFP in the isolation unit even when it is vital to patient welfare and would assist with their work in delivering family-centered care. Taking a strict stance against allowing EVD-negative family caregivers to be with EVD patients during the 2013–2016 West African outbreak, Lappia and Carrick (2017: e5), who worked on the frontline, wrote: ‘The risk of cross-contamination was simply too great. It would almost surely have resulted in the infection, illness, and possibly the death of the caregiver. Our commitment, our medical and ethical duty, was never to risk that additional life’. To prevent cross-infection, relatives who were confined in the same treatment center were allowed to be together in the same ward only if they were confirmed to be positive. Thus, PFP in isolation facilities during an outbreak could be resisted by healthcare workers to protect family members from harm especially when the risks of mortality and morbidity are high.

Against such resistance, we submit that if risks have been minimized for both family members and public health, family members, as individual persons, should be allowed to decide whether to take up the option of PFP based on their own judgment on whether its benefits (for patients and themselves) outweigh its risks. Many people consider familial relations and values to be constitutive of their identity and essential to their lives and as such, may choose to sacrifice their own health to protect these values. In healthcare generally, and particularly at points of serious illness and end of life, these sentiments translate into the wish to be with loved ones in their journey from illness to health or to a dignified death. Of course, not everyone will want to visit an infected relative when it presents significant risks to one’s own health and the health of other family members whom one lives with.

Nevertheless, the behaviors of some family members and other intimates of actual or likely infected patients during recent outbreaks suggest their willingness to bear the risk of infection. During the 2013–2016 West African EVD outbreak, when a symptomatic patient in Sierra Leone ran away from a treatment center, her husband spent a month with her in the bushes, leaving her food and giving her words of courage at a distance, and was praised afterwards by the patient for fulfilling his altar promise to be with her in ‘sickness and in health’ (see online video ‘For Better or for Worse’ in OnOurRadar and New Internationalist, 2017, which captured the reflection of the patient post-outbreak). It is perhaps based on such mutual love and commitments—an ethics of care—that drove people in Singapore to sneak into hospitals to see their isolated loved ones (The New Paper, 2013), and parents in Toronto to protest against the strict isolation of their infected or symptomatic children during the 2003 SARS epidemic (Koller et al., 2006). One parent (Toronto) said: ‘I was never afraid, but I was not going to be separated from her. I made that abundantly clear’ (Koller et al., 2006: 56). Drawing from these
responses to forced separation, we may extrapolate that at least some family members would voluntarily undertake significant personal risks to be with their isolated loved ones during outbreaks of deadly infectious diseases, and be reasonably comforted by the opportunity to do so. PFP in the isolation unit enables family members to fulfill their moral commitments to the patient, and maintain ‘family integrity’, that is, to function and survive as a social unit through highly stressful or traumatic events (Horn and Kautz, 2007).

Thus, in view of familial moral commitments and values, family members should be allowed to decide whether to undertake the risks of visiting or caring for their loved ones in isolation units. To support their decision-making, they should be apprised of the risks, which would include infection and emotional risks related to the visit and the fact that PPE may not fully negate the risk of transmission. To minimize risks of infection and transmission, measures such as assisting visiting family members with the required PPE, and requiring them to undergo home or facility-based quarantine and monitoring of symptoms post-visit should be implemented. Assuming that e-communication is either not available or significantly less effective for minimizing harms and burdens to isolated patients and families, allowing PFP under these conditions would be the least infringing policy, commensurate with the public health goal of limiting spread.

It may be argued that healthcare systems should not allocate scarce resources like PPE and healthcare workers’ time to facilitate PFP during an outbreak emergency. However, if we accept that PFP is necessary to minimize the harms and burdens of isolation for some patients and their families, and that it is the least infringing of isolation and visitation policies, then it is ethically justifiable for healthcare systems to allocate resources to support PFP. Diversion of resources to support PFP should of course not undermine a healthcare system’s ability to maintain the safety of frontline workers and appropriate care for all patients.

**Moral Dilemmas**

Another possible objection to allowing PFP within isolation units during outbreak emergencies is that it would give rise to additional moral issues and familial conflicts. For example, a deep concern of SARS survivors was that they would infect other people (Gardner and Moallef, 2015). Patients in isolation facilities during outbreaks may therefore reject their loved ones’ physical presence even if allowed. Speculatively, if PFP is allowed, it might even become a familial ethical obligation in some societies or cultures such that those who do not take up the option might be seen as uncaring or unvirtuous. Such dilemmas and issues might arise but they seem resolvable by current ethical standards and principles. If patients have the capacity to decide and do not want a relative to visit, or if they had made their objection to PFP known prior to losing capacity, their refusal should decide the matter, in line with respect for patient autonomy. In light of possible pressure from patients or the wider society, healthcare workers can discuss with relatives the benefits and risks of different family presence modes, and should not endorse a position. Ultimately, relatives’ decisions should be respected, reasons for why PFP did not go ahead can be kept confidential and private, and healthcare workers can encourage and facilitate the less risky options of e-presence or physical presence outside the isolation ward (if it is viable for patients and families to communicate as such).

**Conclusion**

This article argues for a family presence policy for isolated patients during outbreak emergencies that include the option of bedside visits or care within the isolation facility. Moral considerations offered in support include minimization of patient burdens and harms, benefits to patients and families, and respecting the choice of individuals to assume risks to be with or for their family members in times of crisis. An additional reason is the promotion of voluntary individual and family cooperation with isolation measures. We have defended PFP within isolation facilities from plausible counter-arguments, particularly potential harms to relatives and the public. Importantly, we have specified the conditions for the implementation of PFP as the least infringing policy on patient isolation and visitation. PFP is least infringing when it is essential to minimize the burdens and harms of isolation for patients and their families; when it is an acceptable and essential option from a family member’s viewpoint to fulfill his or her care commitments to patients; when the risk of patient-to-family transmission has been minimized; and, when it would not impose considerable burdens on public health and health systems. Detailed protocols and monitoring strategies should be put in place whenever PFP is allowed, thus optimizing outcomes and reducing risks.
Postscript

This manuscript was written prior to COVID-19. We knew—as many other infectious disease experts did—that an emerging zoonotic pathogen is lurking somewhere, just waiting to cross the inter-species barrier, but we did not think that our argument above will become pertinent so soon. At time of writing, more than 420,000 deaths due to COVID-19 have been reported worldwide (World Health Organization, 2020). Most of these people have died in hospitals and other healthcare facilities. Due to restrictive visitation policies, many of them died separated from their loved ones. Some healthcare workers took on familial roles such as bedside vigils (Holmes, 2020). Others supported family presence by holding e-communication devices and assisting patients with their use (Goldstein and Weiser, 2020; Wakam et al, 2020). While caring and compassionate, these modes of family presence add to the burdens of healthcare workers. In light of these issues, some facilities have redesigned their e-communication infrastructure so that patients need not rely on healthcare workers, or modified their systems so that families can be contacted quickly and engage in e-presence for deteriorating or dying patients (Martineau, 2020).

Investment in e-communication will help minimize the burdens of isolation and restrictive visitation policies for patients, families and healthcare workers during COVID-19 and future outbreak emergencies. But e-presence cannot effectively substitute for PFP for some patients and their relatives, as we have argued here. We are heartened that in some countries, PFP is supported for particular COVID-19 patients, such as the very young and the dying, on grounds of patient welfare and compassion (Goh, 2020; Halbfinger, 2020; Ng, 2020).

To be clear, we agree that it is justified not to allow PFP due to resource constraints or when the healthcare system is being overwhelmed. What we are arguing against is the categorical prohibition of PFP as the “international “default position”” (Halbfinger, 2020). Public health measures during an emergency situation can be justifiably paternalistic to various degrees (Upshur, 2002). But it is unjustifiably paternalistic or restrictive when, to reiterate, PFP is essential to harm and burden minimization for patients and families, and for family members to fulfill their care responsibilities to the patients; there is no danger of a critical shortage of healthcare resources; and, risks can be minimized for visiting family members and the public. Implementing PFP under such conditions is not only least infringing but also important for public health. It is how individuals, families and communities could survive as a whole during and after a public health crisis.

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Conflict of Interest

None declared.

Note

1. The ethical importance and feasibility of communication with family for isolated patients during outbreaks were raised by the first author of this article as a temporary advisor to the WHO during a 2015 meeting to develop the guidance document.

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