Commentary

Why can't I visit? The ethics of visitation restrictions – lessons learned from SARS

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Abstract

Patients want, need and expect that their relatives will be able to visit them during inpatient admissions or accompany them during ambulatory visits. The sudden outbreak of severe acute respiratory syndrome (SARS), or a similar contagious pathogen, will restrict the number of people entering the hospital. The ethical values that underlie visitor restrictions are discussed here.

Keywords ethics, public policy, sars, selective provider restrictions, visitors to patients

Introduction

The sudden emergence of severe acute respiratory syndrome (SARS) in April 2003 caused much concern and reaction. Refereed medical journals ever since have been rife with articles about SARS. The eventual containment and treatment of SARS has seen a diminution of the massive media publicity and overt public concern. However, fears have recently surfaced about the potential for re-emergence of SARS in the near future. As we confront the potential need to return to more stringent infection control measures once again, this is an appropriate time to reflect on the ethical values that underlay the strict visitation restrictions imposed in hospitals in Ontario during the SARS outbreak and the moderate restrictions in place since SARS. This reflection will facilitate future decision making with respect to visitation restrictions.

When public health trumps civil liberties: the collateral damage associated with victims of SARS

Our infectious disease colleagues are adamant that restricting the movement of people into and around the hospital setting are effective clinical and epidemiological strategies that will help protect both the vulnerable patient population and health care providers themselves, who need to stay healthy so that they may care for their patients. One might argue, then, that visitation restrictions are both enhancing and supportive of public health protection. This position recognizes that there are times when public health protection overrides the protection of individual freedom. It could be argued that visitation restrictions, in light of a potential outbreak of a contagious disease, are ethically sound because of the compelling need to protect public health.

However, even when public health concerns trump individual liberties, the ethical operationalization of this value would demand that 'those whose rights are being infringed' need to be managed in 'an ethical and even-handed manner so that they are not unfairly or disproportionately harmed by such measures' [1].

This is an important and far-reaching consideration because SARS caused collateral damage and we know that the implementation of visitation restrictions will have an impact on a broad range of individuals. Understandably, those patients who were confirmed or suspected of being carriers of contagious pathogens were easily and directly identified. However, there were people who had not demonstrated any risk or epidemiological link to a contagious disease but who experienced quarantine, restriction of movement, inconvenience, loss of pay, and inability to access important and sometimes vital services within the health care system. In fact, there was a general trend within the populace toward

 SARS = severe acute respiratory syndrome

avoiding meetings/gatherings, as well as kissing, hugging and even hand shaking. Clearly, these restrictions are reflective of a loss of civil liberties in the general population and render expressions of caring difficult at a time when people may need them the most.

In a health care institution, visitation restrictions not only affect inpatients but also have an impact on ambulatory patients who must come for diagnostic tests or interventions and who, if deprived access, might develop urgent or emergent conditions. Restrictions are likely to cause distress, anxiety and increased complaints. In fact, on review of the University Health Network corporate complaint database, SARS 1 (period March 28–April 20, 2003) and SARS 2 (period May 12–August 10, 2003) generated a 27% increase in complaints over the expected number of complaints for that time period. Specifically, during this time period there would normally have been 770 calls of complaint, but with SARS 1 and 2 a total of 1052 calls of complaint were received. It should be stressed that these data are over and above the complaints received at each site of the corporation, which were not captured in the database. Ultimately, this is a set of problems that must be managed with sensitivity and clarity (Nyhof-Young and colleagues, unpublished data).

In view of the magnitude of implications of visitor restriction, it is important that policy decisions, at the micro or macro level, consider issues of equity, publicity, transparency and the appeal process. Issues of equity must take into consideration the known facts from a scientific perspective as well as the range of approaches considered. In terms of transparency and due diligence, the rationale behind the policies and how they will be implemented should be as clear and unambiguous as possible. Feedback should be sought from those individuals who would be affected by visitation restrictions, such as staff, patients and family members. The policy must be made accessible, printed and broadly circulated throughout the hospital so that people understand the rules, the rationale for those rules, the processes available to them to assist them in 'living with those rules' and ways to appeal in special circumstances.

Visitation policy developers must realize that there may be exceptional circumstances that demand exceptional latitude. The development of criteria for exceptionality must recognize the need for proportionality, ensuring that criteria are 'relevant, legitimate and necessary … and should be applied without discrimination' [1]. Furthermore, to be consistent with expectations of transparency, the criteria by which exceptionality to the rules of visitation restriction exists should also be published openly throughout the organization for staff, patients and visitors. From our experience with SARS, a corporate policy was developed and there was an expectation that there would be compliance with this corporate policy. However, it was also acknowledged that local patient needs would dictate more or less stringent adherence to these rules, and that the degree of adherence might change quickly without the opportunity for broad notification. For example, although current policy allows for specific times of visitation and numbers of visitors per day, a sudden outbreak might dictate a quick lockdown of the facility without patients or family members receiving prior notice.

Health care workers' duty to care and the duty of institutions to support them

A health care professional has a duty to care, based on several ethical considerations [1] such as professional code of conduct, intrinsic requirements of the work and the acceptance of risk as part of the decision to do a specific type of work. Part of this duty to care for patients encompasses a broader duty, in that one must care for their family as well. Visitation restrictions impede this ability because health care providers find themselves in the awkward position of conveying very private, personal messages between patients and family members, of providing updates and of breaking bad news over the phone, thus losing their ability to convey empathy or judge the amount of support required effectively. Moreover, health care workers, being in direct communication with patients and families, bear the brunt of their anger and frustration regarding any restriction in visitation.

There is an implicit acceptance that reciprocity exists between the hospital organization and the individual staff member [1]. To this end, it is the organization that must accept responsibility for making rules and communicating them broadly to all staff, patients and visitors. Similarly, it is the responsibility of the organization to enforce compliance with these rules; it is not the responsibility of staff, whose primary responsibility is to discharge the duty of care to the patient. The organization also has the responsibility of developing a set of criteria outlining exceptionality and a process to receive, review and adjudicate requests. A process must be developed (together with appropriate resources) so that staff members know who to access for support and are able to do this is in an easy and expeditious manner.

Naming names, naming communities: privacy of personal information and public need to know

In the interests of the public good, there may be times when information must be shared publicly, thereby impinging on the rights of the individual to privacy and confidentiality. With respect to restricted visitation, an ethical argument could be made that visitation restrictions (or latitude thereof) can be instituted generally, without specifically naming names. Although the vigilant observer might be able to identify a specific person from a changed application of the rule, the organization cannot reasonably be expected to guard against every possible identification, but every effort should be made

to protect the individual from easy identification. For example, if a family is allowed to visit a patient whose death is presumed to be imminent (within the next 24 hours), then the patient's identity should be protected by using privacy strategies. Efforts to protect the patient's identity are consistent with the ethical value of 'protection of communities from undue stigmatization' [1].

SARS in a globalized world

Given the risks associated with contagious pathogens and the easy mode of transmission globally, it is important that there be consistency in management. The ideal situation would be a consistent global approach to the management of each and every contagious pathogen. The notion of universal management strategies is very sensible (e.g. universal precautions with blood-borne conditions such HIV). However, given the political and economic disparities across the world as well as the lack of knowledge (particularly of newly evolving pathogens), a standardized approach is not possible.

The experience of SARS indicates that some patient populations require a level of vigilance that is more stringent than that required in others. For example, those individuals who reported recent travel to high risk areas, and those who worked in quarantined or contaminated hospitals or who exhibited clear symptoms (e.g. fever, persistent cough) were scrutinized with more vigilance and were in fact treated differently than other visitors, until they were cleared through the screening process. This type of variability in vigilance demands ethical management of differences, and there is a need to guard against overt bias or discrimination creeping into the process.

It is difficult to expect that both standardization of approach and variability in approach can easily coexist, but the operational challenge is to exercise awareness of the ethical values discussed above and the appropriate due diligence in the implementation of processes.

Conclusion

It is ethical to accept that public health protection trumps individual rights to liberal visitation. The rationale for this position must be fully outlined to patients, visitors and staff.

In responding to visitors who may be deprived of visitation, it is ethical to recognize that there may be exceptional circumstances that demand exceptional latitude. A set of criteria outlining exceptionality should be developed, as should a process to receive, review and adjudicate requests. In the interests of equity, an appeal process should be made explicit and transparent to all. This information should be well publicized to staff, patients and visitors in a consistent and sensitive manner. Every reasonable effort should be made to protect the individual patient's identity and their specific health status should exceptionality be considered.

It is ethically the responsibility of the organization to enforce compliance with restricted visitation and a corporate department should be assigned this task.

Although it is recognized that standardization in the application of visitation restrictions is necessary, there is recognition that there may be circumstances that would require deviation from the corporate position.

Competing interests

The author declares that she has no competing interests.

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