The "Open" Intensive Care Unit: the Challenge Continues

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Restricting visiting in ICUs is neither caring, compassionate, nor necessary.
Donald M. Berwick and Meera Kotagal, JAMA (2004)

6.1 Introduction

Nearly 10 years have passed since Hilmar Burchardi, past president of the European Society of Intensive Care Medicine, wrote in an editorial in *Intensive Care Medicine* that "it is time to acknowledge that the ICU must be a place where humanity has a high priority. It is time to open those ICUs which are still closed [1]".

The intervening period of time has undeniably brought about some changes in the direction indicated by Burchardi, but the "opening" of intensive care units (ICUs) even if no longer a "dream" is certainly still far from being a full "reality".

The literature gives a patchy picture of visiting policies in the critical care setting. The latest available percentages of adult ICUs without restrictions on visiting hours are 70% in Sweden [2], 32% in the USA [3], 23% in France [4], 22% in the UK [5], 14% in Netherlands [6], and 3.3% in Belgium [7]. Italian ICUs overall maintain very restrictive visiting policies. However, over the last 5 years, in Italy there has been perceptible change in this field: daily visiting time has essentially doubled (from 1 to around 2 h) and there has been a substantial increase in ICUs allowing 24-h visiting (from 0.4% to 2%) [8,9].

As regards children, well into the 1960s their admission into hospital inevitably entailed their separation from parents and family [10,11]. Visiting was severely restricted or even prohibited, being considered dangerous or simply of no value. Aspects such as disruption of the intrinsic bond between child and parents or the loss of the parental role were practically unknown or disregarded as irrelevant. As for pediatric ICUs (PICUs), a US study in 1994 showed that 57% of 125 units restricted visits to brief daily periods [12]. Another North American study found that eight PICUs out of 12 limited visits to varying extents and that only two had an unrestricted visiting policy [13]. In Italian PICUs, the median daily visiting time

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for parents is currently 5 h; 12% of units have unrestricted policies and 59% do not allow the constant presence of a parent even during the day [14].

6.2 The Liberalization of Visiting Policies in Intensive Care Units

6.2.1 The Case in Favor

For many doctors and nurses the term "open" ICU still represents a kind of oxymoron, i.e., literally an unreal condition in which noun and adjective are in clear and irreconcilable opposition. This point of view is largely consistent with past history. From the time of their creation less than 50 years ago and for many years thereafter, ICUs were "closed" wards where access for family members and visitors was looked on unfavorably and was therefore strictly limited. This strategy was frequently motivated above all by fears regarding the risk of infection, interference with patient care, increased stress for patients and family members, and the violation of confidentiality [1,15].

So, for many years admission of a patient to ICU followed what we might call a "revolving door principle", i.e., when the patient came in, their family was sent out. The logic behind this entrenched behavior was that the strategic objective of prime importance, i.e., the life and health of the patient, justified resorting to a kind of "sequestration" of that patient. The reduction or abolition of contacts with the patient's affective world was considered a reasonable price to pay to obtain the far greater advantage of life and health themselves.

However, not only are the reasons for restricting visits groundless [1,15], but there are strong arguments in favor of liberalizing access to the ICU for patients' families. Current knowledge has shown that separation from loved ones is a significant cause of suffering for the ICU patient [16,17], and that for the family to be allowed to visit at any time represents one of the most important needs [18–20]. On this subject, it is interesting to note that ICU doctors and nurses largely underestimate [17,21] both the need of the sick person to have their loved ones nearby and the relatives' need for information and proximity (which are the main needs of families of ICU patients, together with assurance, support, and comfort) [19–21].

Regarding the pediatric world specifically, separation from their parents has long been recognized as the greatest source of stress for hospitalized young children [22]. From the point of view of the parents, in addition to uncertainty regarding their child's condition and outcome, a major source of stress is the loss of their parental role [22]. Being with the child is, together with frequent and accurate information about their condition, the most important need of parents; often their priority is not constant presence at the child's bedside but the freedom to visit their child when they can or wish to [23].

Separation from loved ones is often for the patient a further and unjustified "price to pay" on top of the illness or acute event which caused the admission to ICU.

Alongside the patient's suffering there is also that of their family, which is often not recognized or given scant consideration: for example, symptoms of anxiety and depression were found in 73% and 35% of family members, respectively [24]. Moreover, post-traumatic stress symptoms consistent with a moderate-to-major risk of post-traumatic stress disorder (PTSD) were found in 33% of family members [25]. It is important to stress that the suffering of families is not a transitory event but can in fact persist long after the patient is discharged. Evidence of this is that at 6–12 months after discharge, 27% of parents of PICU-admitted children were assessed to be at high risk for PTSD (as compared with 7% of parents of ward-admitted children) [26].

Numerous data suggest that the liberalization of access to ICU for family members and visitors [18,27] is not only in no way dangerous for patients, but is on the contrary beneficial both for them and for their families. In particular, an unrestricted visiting policy causes no increase in septic complications [28,29], while cardiocirculatory complications, anxiety scores, and hormonal stress indicators are significantly lower [28]. It also has the positive effect of sharply reducing anxiety in the families of patients [30]. For instance, mothers of children admitted to an "open" PICU have lower stress indicators than those of children in a PICU with "limited access" [31].

6.2.2 Visiting by Children

Children visiting family members who have been taken into intensive care, is also, under certain conditions, a positive and welcome occurrence. On this subject, a nationwide multicenter study in Sweden found that all the ICUs covered by the study had a positive policy regarding visits by children to adult patients, though 34% of the wards had some *de facto* restrictions in place [2]. Moreover, it should be considered that there are no real reasons for systematically discouraging visits by siblings to children admitted into intensive care: the presence of a sister or brother has a positive and reassuring effect on the patient. Apart from certain specific exceptions (e.g., when the visitor has a contagious infection), if the child is suitably prepared and supported by the family context (and by other "powerful" contexts, such as their school), the visit to an ill sibling helps to dispel the children's fears and fantasies of loss or death, and reassures them of their parents' continuing attention [11].

6.2.3 Procedures and Cardiopulmonary Resuscitation

A recent survey found that in Italian PICUs there is a clear tendency to substantially limit the presence of parents during procedures (even ordinary nursing ones) and cardiopulmonary resuscitation [14]. In 38% of units parents were not normally allowed to be present at the bedside during ordinary nursing procedures such as endotracheal suctioning. In the case of invasive procedures such as inserting a cen-

tral venous catheter and in the case of cardiopulmonary resuscitation, the presence of parents was permitted only in 3% and 9% of units, respectively.

This topic has recently been reviewed by Dingeman and colleagues [32]: most parents wish to have the option to remain with their child during invasive procedures and resuscitation, and those who have done so would repeat their choice in the future. Parents can calm or emotionally support their child and help caregivers. Moreover, reduced anxiety and help with the grieving process are two of the main benefits for parents permitted to be present during procedures or resuscitation.

Although the presence of family members during resuscitation has been recommended [33], it is not unanimously considered a positive thing and continues to raise concerns among physicians and nurses [34,35].

6.3 The "Open" Intensive Care Unit

6.3.1 Ethical Aspects

There is in fact no solid scientific basis for limiting visitors' access to ICUs [1,15,18,27]. Moreover, on both ethical and clinical grounds, only serious public health risks can exceptionally justify restricting visits [36].

Even in the area of health, the choices we make, the reasons behind them, and the actions that result must be weighed up to assess their acceptability on an ethical level. The philosopher Emmanuel Levinas wrote [37] that the capacity to recognize "the face of the other" generates responsibility towards, and relationship with, them. It is possible and it is fitting to transpose these terms – responsibility and relationship – even into the complex environment of intensive medicine, giving rise to new gestures and language. It is in this perspective that the choice of the "open" ICU makes sense also on an intrinsically ethical level and thus it becomes necessary, precisely because it more fully addresses not only the needs of the other, but also the valuing of, and respect for, that person's life.

Another element to be considered in the area of ethical aspects – certainly for adults and teenagers – is respect for autonomy. We must clear up a misunderstanding here. In allowing the presence of family and visitors in the ICU, we doctors and nurses are not making any concession to the patient. Instead, with this action we recognize a clearly defined right of the patient. The patient – where this is feasible – should be given the option to decide which people are particularly significant for them and who they therefore wish to have nearby in the difficult period of sickness. A significant proportion of admissions to the ICU is not triggered by sudden or acute events, but rather these are scheduled events (major surgery, transplants) or represent a predictable stage in the progression of a chronic disease (oncological, cardiac, respiratory, neurological, and so on). There is therefore plenty of scope for consulting patients as to their wishes so that they may decide in advance which visitors are important to them.

6.3.2 Experience in the Field

With the knowledge that liberalization of visiting hours offers beneficial effects for both patient and family, the necessity of "opening" ICUs has been pointed out authoritatively and repeatedly [1,15,18]. In particular, it has been recommended that visiting in PICUs should be open to parents 24 h a day [18]. However, from the picture outlined previously, we may deduce that in many countries there is not yet a full awareness that the presence of loved ones at the bedside is beneficial for the patient and that in the critical care setting family is actually a resource rather than a hindrance [38,39].

The experience of units that have already liberalized their visiting polices provides some interesting information. A French study, for example, highlights three issues [40]. First, the median visit length is around 2 h a day and the majority of family visits are mostly concentrated in the afternoon and evening (so there is not a sort of "invasion" of ICU). This probably happens because relatives, despite this period of particular difficulty and suffering, still have to face – sometimes having to resort to complex juggling – all the commitments imposed by normal working and family life. Second, neither nurses nor physicians perceive open visitation as disrupting patient care (even though it may induce moderate discomfort among nurses due to possible interference with patient care). Finally, most family members report that the 24-h policy lessened their anxiety. In addition, a recent Italian survey found that most ICU staff members view the "opening" of the unit positively, and on the whole maintain this opinion 1 year after the policy change [41].

6.3.3 Not Just a Question of Time

The liberalization of visiting policies is only one aspect of a more complex issue and the author would like to propose a shift in perspective. Creating the "open" ICU is not just a question of time: we also need to consider "openness" in terms of physical and relational dimensions. The "physical dimension" includes all the barriers recommended to or imposed on the visitor, such as no physical contact with the patient, gowning procedures (of no value in infection control [1]), and so on The area of "relationships" involves the communication – often fragmentary, compressed, or even nonexistent – among ICU staff, patient, and family. If we also address these aspects, an "open" ICU may be defined as a unit in which one of the caregivers' objectives is a carefully considered reduction or elimination of any limitations imposed on these three dimensions (temporal, physical, and relational) for which there is no justified reason [42,43].

Being able to see the work carried out in the ICU with their own eyes thus helps to give the family reassurance, strengthening their conviction that their loved one is being properly looked after around the clock. In addition, "open" access makes for better communication [27] with nurses and doctors as well as increasing the family's trust in and appreciation of the care team. It may inevitably be that, in certain circumstances, family members exhibit an "overvigilant" or even

hostile attitude [27], which may be in response to a closed stance adopted by the ICU team (in the form of restricting information, excluding family from the decision-making process on key issues, and so on). It is in the interests of the patient that these relationships be carefully restored to mutual trust and respect.

6.3.4 A New Language

Working in the ICU and the endeavor to create a patient-centered ICU [18,44] can be enriched with new words and actions. For instance, the terms "welcome" and "hospitality" are rich and evocative ways of referring to the way we relate to the other, even in the context of a hospital. They can be "inflected" in the specific reality of the ICU and translated into behavior or attitudes. An "open" ICU offers the possibility to devise new gestures and language, rich in humanity. A first example pertains to the "body": touching the patient's body, holding them (even if still intubated and on a ventilator, or on noninvasive ventilation), feeding the patient a little, and so on, are gestures of enormous value both on the level of the relationship and on the therapeutic level. An effort is required to create the conditions to make this possible, with all due safeguards, but it must be made evident that the patient's body is not something "expropriated" and inaccessible to loved ones.

We live in a society which does not like to "see people die," which censors death and hides it away. But no area of medicine highlights as critical care does that the practice of medicine is governed by limits. Almost every day in the ICU staff touch the limit with their hand and must look death in the face. In the light of the considerations explored previously as to what an "open" ICU means and the reasoning behind it, "death" too may be approached in a different way, with a different "language" and gestures from the customary ones. We are generally accustomed to the gesture of "delivering a body" after death, but we can instead create the conditions whereby "the person is accompanied" at the time of death. The semantic and symbolic difference is obvious, but experience shows that there is also a profound practical difference between the two. Providing the circumstances permit it and if death is not an acute and unexpected event, it is important to allow relatives to be with their loved one even in the terminal phase of life, staying close by, touching, caressing (or holding them, in the case of a child), speaking to them with their own intimate gestures and words. These are heartrending, unutterable moments – literally "unspeakable" – but of enormous importance. Moreover, all these gestures of leave-taking represent the first step on the way to working through the grieving process.

6.3.5 Tackling the Difficulties

"Open" ICUs may therefore provide fuller and more appropriate responses to some of the needs of patients and their families. However, it would be wrong to play down the difficulties or inconveniences involved in an innovative choice such as this. These

are for the most part associated with habits and "cultural" aspects, which constrain both the medical team and the patient's family. We should also bear in mind that personality traits or habits such as obtrusiveness, aggressiveness, or mistrust almost always tend to be exacerbated by new, stressful situations such as the serious illness of a family member. This whole matter is often dealt with in a rigid fashion, with reference more to the regulations (a true "totem" of hospital life) than to the meaning of the events and a search for balanced and rational solutions.

An "open" ICU does not, however, mean an ICU "without rules" [42], and it is both practical and necessary to draw up some guidelines. Visitors should be required not only to show the greatest consideration for all the patients in the unit, but also to follow some basic rules concerning hygiene (e.g., to wash their hands before and after the visit); security (e.g., not to touch equipment or vascular access lines); and operations (e.g., to move out of the way during emergency maneuvers). Each individual ICU may draw up its own rules and modify them over time on the basis of a critical assessment of their own operations. It is also important to give the medical team time and space of their own, allowing free communication and full respect of confidentiality, but also some indispensable breaks not constantly punctured by interruptions.

Finally, we should not deny or underestimate the possible difficulties that ICU staff face (particularly nurses) in opening the unit, mainly to do with a different style of relations with visitors and the burden for staff members of learning to work under the eyes of family members.

6.3.6 The Way Forward

In the author's view, there are at least four courses which we must now pursue [43]. The first concerns information and education of ICU physicians and nurses. We must invest time and resources in increasing knowledge of and sensitization to these issues (visiting policies, patient and family needs, patient-centered ICUs, and so on) among caregivers.

Second, there is also a great need for research into these issues and, in particular, investigation of any difficulties which liberalizing visiting could cause for ICU staff (e.g., anxiety, stress, and overwork). It is essential to create a picture of the problems and understand their causes and extent, to identify possible solutions and offer nurses and physicians appropriate support.

Third, communication skills must be fully recognized as a specific area of professional competency for ICU caregivers, which needs to be improved or updated. In addition, as recently recommended [18], ICU staff should also receive training in conflict management, meeting facilitation skills, and assessment of family needs and family members' stress and anxiety levels. Today, the cultural baggage of the intensivist can no longer be limited exclusively to practical "know-how": in the care of the ICU patient, clinical skills and familiarity with technology are a necessary but not sufficient condition. Finally, unrestricted visiting should be made a requirement for a hospital's accreditation in the public health service.

6.4 Conclusions

Despite the many objections considered valid until recently (mainly infection risks, interference with patient care, increased stress for patient and family members, violation of confidentiality), there is no sound scientific basis for limiting visitors' access to critical care units. There is now wide consensus that the liberalization of visiting in ICUs/PICUs is a useful and effective strategy to respond to the needs of patients and their families. However, the "open" ICU is not just a question of visiting time: we also need to consider "openness" in terms of physical and relational dimensions.

It is not always easy to "open" our ICUs. It necessarily involves disrupting the rhythms and rules of a well-established and reassuring tradition. It is a choice which commits us to coming up with original solutions for each individual situation, which will require regular monitoring, and need to be renewed and remotivated over time. But what is needed above all is a certain degree of cultural change and serious consideration regarding the value and quality of relationships with patients and their families.

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