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ICU Professionals' Experiences of Caring for Conscious Patients Receiving MVT

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Abstract

Over the last decade, caring for patients who are conscious while receiving mechanical ventilator treatment has become common in Scandinavian intensive care units. Therefore, this study aimed to describe anesthetists', nurses', and nursing assistants' experiences of caring for such patients. Nine persons were interviewed. A hermeneutic method inspired by Gadamer's philosophy was used to interpret and analyze the interview text. Staff members found it distressing to witness and be unable to alleviate suffering, leading to ethical conflicts, feelings of powerlessness, and betrayal of the promises made to the patient. They were frustrated about their inability to understand what the patients were trying to say and often turned to colleagues for help. When caring for conscious patients, it takes time to get to know them and establish communication and a trusting relationship.

Keywords

hermeneutics, mechanical ventilation, conscious, nurses, relationship

Caring for conscious patients receiving invasive mechanical ventilator treatment (MVT) in intensive care units (ICUs) has become more common because light or no sedation has several medical advantages. Light sedation

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routines and strategies such as daily awakening of patients have been studied. Kress, Pohlman, O'Connor, and Hall (2000) and Kress et al. (2003) found that patients who are awoken from sedation on a daily basis are a shorter time on MVT and in the ICU. However, this is contradicted by the results of Mehta et al. (2012), who revealed that daily awakening does not reduce time on MVT or in the ICU. Girard et al. (2008) demonstrated that daily awakening including spontaneous breathing led to a better patient outcome than the standard approach and routines. Strøm, Stylsvig, and Toft (2011) also compared standard sedation and daily awakening. They found that patients who were woken on a daily basis and breathed spontaneously during MVT were not at an increased risk of long-term psychological problems. This finding was in accordance with Jackson et al. (2010). Another sedation regimen for patients assessed as able to tolerate it during MVT comprises no or light sedation. According to Strøm, Martinussen, and Toft (2010), patients on MVT who receive no or only light sedation are a shorter time on the ventilator and in the ICU. Previous research on patients' experiences of being conscious during MVT (Karlsson, Bergbom, & Forsberg, 2012; Karlsson, Lindahl, & Bergbom, 2012) has demonstrated that the endotracheal tube and probes caused pain and panic when patients did not get enough air and that communication was difficult, as such patients are unable to speak (Bergbom-Engberg & Haljamäe, 1989; Foster, 2010; Karlsson, Bergbom, & Forsberg, 2012; Karlsson, Lindahl, & Bergbom, 2012; Samuelsson, 2011). According to Egerod (2002), constant supervision by nurses is more favorable for patients than sedation. This may indicate that caring for patients who are conscious while receiving MVT places different demands on nursing staff compared with unconscious patients. In previous studies (Bergbom-Engberg & Haljamäe, 1993; Börsig & Steinacker, 1982; Wojnicki-Johansson, 2001), both nurses and patients have reported frustration; nurses about being unable to understand the patient and patients about their inability to communicate with nurses or family members (Karlsson, Forsberg, & Bergbom, 2010).

A previous study (Karlsson et al., 2010) found that relatives felt uneasy when witnessing the patient's facial expressions of discomfort, and it was assumed that such stress can be transferred and cause distress among nurses and physicians. This is supported by a video-recorded interview with patients undergoing MVT in an ICU. The researchers' interpretation was that the patients' eyes indicated grief, their body position was tense, and their facial expression stiff (Karlsson, Lindahl, & Bergbom, 2012). It is plausible that this is interpreted in the same way by staff, leading to the question of whether they find it distressing to care for conscious patients during mechanical ventilation. Another question is whether caring for conscious patients requires a different type of attention, assistance, and ethical considerations. Therefore,

we aimed to investigate staff members' experiences of caring for conscious patients to understand the challenges they face. As far as we are aware, previous research has not focused on anesthesiologists', nurses', and nursing assistants' experiences of caring for such patients. This knowledge is of importance for training and supporting practitioners as well as managing and developing the care by means of, for example, in-service education.

Theoretical Framework

Patients in an ICU are extremely vulnerable, and inability to speak when intubated limits their ability to mediate their wishes and needs. They are thus completely dependent on the nurses' goodwill, knowledge, skills, and sensitivity to their condition and needs. Conscious patients may require more attention and presence on the part of the nurse to communicate their needs. It is known that during mechanical ventilation patients may experience discomfort and occasionally panic or fear. If the nurse, due to workload, cannot meet patients' needs, and assisting patients to endure, patients may feel worried or abandoned (Bergbom-Engberg & Haljamäe, 1989; Foster, 2010; Karlsson, Bergbom, & Forsberg, 2012; Karlsson, Lindahl, & Bergbom, 2012; Samuelsson, 2011). Karlsson, Forsberg, and Bergbom (2012) found that nurses can help patients endure by "standing by" them. Standing by is a caring action implying that the nurses are present in the deepest sense of the word, demonstrate willpower, courage, attentiveness, and a friendly approach, as well as mediating calmness and eagerness to be together with the patient to fight for survival and recovery. Nurses can mediate trust, hope, and love aimed at helping and showing patients that they want what is best for them. Abandonment may cause suffering and in the theory of suffering Eriksson (2006) describes the suffering of care, the suffering of illness, and the suffering of life. Witnessing suffering may also create suffering for the nurses, especially when alleviation is not possible, which can result in ethical dilemmas as it is essential not to harm patients.

Method

The aim of this study was to describe anesthetists', nurses', and nursing assistants' experiences of caring for conscious patients receiving invasive MVT in an ICU, as we wanted to understand what it is like to care for these patients. A hermeneutic approach inspired by Gadamer (1989) was used to interpret the interview text. According to Gadamer, human beings interpret continuously and cannot exist without so doing. A text can be approached from two horizons; that of the reader and that of the text. The present researchers'

pre-understanding is part of the interpretation, builds on the above-mentioned theoretical framework and comprises many years of experience of working in an ICU, teaching, and previous research.

Approval for the study was granted by the Regional Ethics Committee at the University of Gothenburg (552-07). All participants were informed verbally and in writing in accordance with the Helsinki Declaration (World Medical Association, 2008). Quotations are included in such a way as to ensure the participants' confidentiality.

Setting

The study was carried out in a general ICU comprising 10 beds, but staffed for 8 patients in a county hospital in Sweden. A total of 770 patients were cared for at the unit in 2011, 188 of whom received invasive MVT. Approximately 50% were not sedated or received only light sedation, that is, conscious according to Motor Activity Assessment Scale (MAAS). The most common diagnoses in conscious patients were epiglottitis, sepsis pneumonia, multiple trauma, airway obstruction, carotid surgery, stroke, chronic obstructive pulmonary disease (COPD), and cancer of the larynx. The duration of the MVT was 2 to 23 days. During the study period, 52 nurses, 53 nursing assistants, and 24 anesthetists were employed in the ICU. Nurses and nursing assistants usually care for more than one patient, which also applies to those receiving MVT. The sedation strategy has been in place since 2002. Some patients are administered Propofol® and Fentanyl®, while others receive only Clonidil® or Morphine® when necessary and some receive no sedation or analgesic whatsoever. All conscious patients undergoing MVT have a score of 3 to 4 on the MAAS (Devlin et al., 1999).

Participants and Procedure

The three nurse managers invited all nurses, nursing assistants, and anesthetists who fulfilled the inclusion criteria to participate in the study. The inclusion criteria were as follows: working in an ICU for the previous 3 years and having cared for conscious patients who had been assessed as 3 to 4 on the MAAS (Devlin et al., 1999) during MVT. Those who expressed an interest received further information and were contacted by the researcher, after which nine agreed to participate. The participants' ICU work experience ranged from 9 to 25 years ($M = 16.7$) and they were aged between 38 and 54 years ($M = 47$). The participants gave their written informed consent before the interview. Although the team around the patient consists of more than these three professional categories, these were selected because they spend most of their working hours

caring for the patient. Anesthetists usually visit the patient regularly to prescribe treatment and check medical status and also decide about sedation. Physicians' prescriptions influence nursing care, as nurses have to carry them out and report on the patients' status to the physician. Together with the assistant nurses, these three professions work as a team.

The interview began with an open question: Could you please tell me about your experiences of caring for a patient who is conscious while receiving MVT? Follow-up questions were then asked, such as, "Please tell me more" or "Can you explain?" The interviews were conducted by one of the authors during the physicians' working hours and immediately before or after nurses' and nurse assistants' shift. All participants had been informed about the study and were well prepared to communicate their experiences. Therefore, some of the interviews only lasted about 20 min, although others took approximately 40 min ($M = 28$ min, $r = 18$-41 min). The interviews took place in a private room at the ICU, were audio-taped and transcribed verbatim shortly after. Data collection began in February 2012 and continued until March 2012. One of the authors was employed in the ICU but had been absent for about 10 months at the start of the study.

Interpretation and Analysis

The transcribed interview text was read several times to allow the researchers to become familiar with the content and experiences described. After this first reading, (Koskinen & Lindström, 2013) focused on the question: What did staff members experience when caring for conscious patients who were receiving invasive MVT? This reading revealed that a different form of caring is needed for conscious patients. In the third reading, new questions were posed, such as "What kind of care is necessary?" "What obstacles exist?" and "What kind of care alleviates patients' suffering?" The answers were somewhat complex, which required returning to the theoretical framework and what had been previously understood.

The two authors individually interpreted the content of the text and the participants' descriptions of their experiences of caring for conscious patients. The interpretation process comprised a movement between each individual interview and the whole text as well as between parts of each interview and the whole, including a movement between pre-understanding and a "new" understanding.

Results

Our interpretation was that the staff found it difficult to witness the patients' suffering and stress. It was their duty to alleviate suffering, but not knowing

how to act and care for the patients to make them more comfortable was experienced as frustrating. This resulted in a feeling of powerlessness, despair, and the belief that it was wrong to cause suffering by allowing the patients to remain conscious, which was contrary to their values and beliefs. On the other hand, the text also revealed that the treatment was in the patients' best interest, as it prevented complications and promoted recovery. The following themes were identified: *It is distressing to witness the patients' stress and suffering; Feeling frustration due to not being in control of the situation; Receiving and losing trust and confidence; Being there for the patient; Needing time to learn a new way of caring;* and *Allowing time for rest, sleep, and privacy.*

Quotations are examples of part of individual statements, to illustrate the theme.

It is Distressing to Witness the Patients' Stress and Suffering

The staff found it difficult to watch the patients' stress and suffering, which in turn caused them frustration, as they felt sympathy for the patient. The patient's gaze and facial expression; grimacing, perspiring, lined forehead, and high breathing frequency indicated unease. Furthermore, the patients were perceived as vulnerable and exposed. It was stated that patients sometimes exhibited involuntary movement in their arms and legs, thus had to be constantly monitored to ensure that they did not remove medical technical equipment. The staff were aware of the patients' suffering and stress and wanted to help and make them as comfortable as possible. The inability to relieve patients' suffering leads to feelings of powerlessness and concerns about violating them. The staff members stated that they were able to objectively assess the patients' condition but did not know how the patients themselves felt.

> You suffer with them, you have to be alert all the time, stay close to them so that they don't pull out things and many become stressed when awake. I think that more are stressed than calm. (Nursing assistant [NA] 2)

> I can feel powerless in relation to the patient due to being unable to help. I detest being unable to help, I want to help as much as I can. (Nurse [N] 1)

Feeling Frustration due to Not Being in Control of the Situation

Being unable to assist and pay undivided attention to patients due to the workload was interpreted as frustration on the part of the staff due to inability to provide good care. Being in control and having time for the conscious

patient is difficult if there are several patients in the room or a new critically ill patient arrives. The nursing assistants said that they are pulled in different directions and unable to monitor the patient when their attention and activities must be focused elsewhere. They are forced to leave the conscious patient alone, which gives rise to insecurity and fear of betraying the patient's trust. The staff members underlined the need for improved planning and communication between themselves and the physicians. Different instructions from physicians and a lack of long-term planning complicated the nurses' and nursing assistants' work. The physician on a new shift frequently changes the care plan, but the nurses want to change back to the previous one if things do not function properly.

The participants emphasized the necessity of being active and committed when caring for conscious patients to recognize changes in their medical status. They had to remain close to the patients at all times to make them feel secure. Furthermore, communication is important and requires experience and continuity of care in terms of the same staff, as patients and staff together find a method of understanding each other. Staff expressed the frustration they experienced when unable to communicate with and understand what the patient wanted to say. At times they were helped by next of kin while physicians sought information from nurses and nursing assistants.

> It's frustrating to work on a ward where so much happens and you have to check on someone behind you. Constantly. You would need eyes in the back of your head. It's most frustrating. I have to say that it's something that frustrates me, I want to be in control, I think everybody wants that, there's nobody who doesn't want it. I'm worried that something will happen, it makes me feel frustrated. If the patient is awake in a respirator and trying to reach the tube, I have to sit there and hold the patient's hand and perhaps talk a little and things like that. (NA 1)

> I think it's very difficult and I often get help from a nurse who understands the patient better than I do, they often interpret for me. The biggest problem with ventilator treatment is that the patient is unable to communicate verbally. (Anaesthetists [A] 1)

> I think it's often the case that when the doctors enter the ward you may be administering a bolus injection and the patient is calm and it sometimes happens that there is a change of doctor and you think that it [the current care plan] is a good thing, that it works, then the new doctor comes and doesn't think that it works and rejects it . . ." And then they change it all. Sometimes it feels as if more or less everything depends on the doctor. We try to stick to a care plan, or something may have been agreed in the morning, sure, but things

can happen that make it necessary to change but you have to be able to change back again if you see that it doesn't work. But you sometimes notice that a lot of things happen when there is a change of doctor. (N 2)

I think that at such times there should be more staff around the patients both for the patients' and our own sake. . . Because you feel pulled in different directions, even if I tell the patient that I'm here behind the curtain, you feel as if you need to be there. (NA 3)

Receiving and Losing Trust and Confidence

The participants stressed that as the patient's life was in their hands, they had to act in a manner that inspired confidence and trust. The staff stated that it is important to establish contact with patients who shut themselves off, seem exhausted, refuse contact, and appear to have given up, despite repeated efforts on the part of the staff. Staff are aware of the need to build a trusting relationship with the patient and that there may be a lack of trust when the patient refuses contact.

Some shut themselves off a bit and I suppose it's to be able to endure the situation. Especially when they have been there for some time and find it exhausting. And of course it's arduous in the long term, especially if we can't understand them. If you imagine yourself in their place, I believe their situation is awful. (NA 1)

and some are . . . extremely tired and more or less closed so there is no eye contact . . . with anybody . . . and then you have to try to find different ways, determine whether they seem closed and don't want contact or . . . I interpret it as lack of trust, actually! They have given up on us, sometimes as a doctor you're not the right person but perhaps it's the nursing assistant who spends most time in the ward, because you can see that they relate to some staff members . . . who can communicate to them that "there are ways in which we can help you. (A 3)

They hand over their lives and you must never let them down. It's the greatest trust anyone can give and you must never betray that trust no matter how tired you are when on duty." (N 2)

Being There for the Patient

It was necessary to remain physically close to the patients at all times, talk to them in a reassuring way, and explain what is happening to calm them. Closeness is important for ensuring that the patients feel that the staff

members are there for them, which demands not only physical presence but also presence in a deeper sense. This sometimes means sitting at the bedside and holding the patient's hand, standing near the bed, explaining and talking reassuringly to mediate peace and security. Closeness also means interpreting what the patients need and sometimes it can be leaving them alone while at the same time keeping watch over them.

When they became aware that the patients found it difficult to cope without sedation, withdrew and avoided contact, the staff members applied various strategies to resolve the situation, such as explaining and informing about different matters. They also enlisted the help of staff who "knew" the patients and together tried to find solutions to reduce the stress and discomfort. Even when establishing contact was difficult and they had to repeat themselves, they believed that the patients understood that they had not given up but continued trying.

> I try to be available at all times and be with the patient. (N 2)

> Always demonstrating that we are here, even if the patient does not want me to sit and hold her hand. It's part of basic security, as it's essential for staff to demonstrate that they can be trusted, because the patient hands everything over to them, breathing, circulation and all they need for their own survival. (N

> You feel as if you need to be there. I think that there needs to be more [staff] when patients are completely awake to make them feel secure and that it will work. (NA 3)

Needing Time to Learn a New Way of Caring

The participants believed that they have insufficient sedation—how the patients feel, their medical status, and whether it is better to be conscious while on MVT. They considered that the consequences for nursing care were disregarded. It is easier to care for patients who are completely sedated, as they lie still and are "knocked out." This gave the participants a sense of being in control. On the other hand, they stated that conscious patients are less difficult to talk to, as they are more lucid. Despite the fact that staff found it less complicated to care for completely sedated patients, they derived greater satisfaction from caring for conscious patients, as they could involve patients and inspire hope of recovery. However, caring for conscious patients takes time to learn. The physicians, for their part, reported that caring for a conscious patient during mechanical ventilation is more humane than technological, as patients can play an active part.

> We need to learn anew and it takes time. It's a different way of working. And it's not only for ourselves. I feel that we need time. Such as learning to communicate and understanding a little about their needs. Presence and things like that. A different mode of working. It feels safer when patients are conscious. You know a bit more about how they behave and . . . the pattern is similar when they are conscious on a ventilator. You recognize the signs and when it's not going well. (NA 3)

> I think in that way intensive care becomes, how shall I put it, more humane instead of technological, and you see the patient as a person rather than one of the technical gadgets. (A 2)

> Over the years I have gained a greater appreciation of patients being awake and being able to talk to them. (N 3)

Allowing Time for Rest, Sleep, and Privacy

One way of alleviating patients' suffering was leaving them alone and letting them rest and sleep, preferably in a small room, as well as paying attention to signs of fatigue. The participants regarded a good night's sleep as essential for physical and mental recovery and therefore tried to activate the patients during the day. Patients who were unable to sleep became so exhausted that they began to panic, thus depleting all their resources. It was also important that the patients were calm, free of pain, able to tolerate the endotracheal tube and ventilator. They also stated that they tried to give privacy to patients who felt comfortable being alone by making them agree to use a bell but were at the same time attentive to their condition.

> So that they don't have to . . . tire themselves out completely . . . to give them a chance . . . to rest and relax, I think we have to be very attentive, because if they . . . tense up and lie almost on top of the sheets . . . it's important that we stop it at an early stage before they start to panic . . . (A 3)

Discussion

Patients' suffering and expressions of panic result in an ethical conflict as well as feelings of powerlessness and of betraying the patient and the promise to care. Lévinas (Kemp, 1992) holds that a human being's facial expression makes "the other" responsible, which was expressed by the participants in the present study. They found being confronted with the patient's suffering difficult, as witnessing others' suffering leads to personal suffering. The participants therefore tried to do whatever they could to take responsibility for the

other and alleviate suffering. Eriksson (2006) stated that suffering can be caused by abandoning the patient. In particular, the nurses considered it of the utmost importance not to abandon patients but be present and attentive to their medical status and needs and do what they could to alleviate discomfort and suffering. This was understood as an ethical obligation.

When nurses became aware that they could not alleviate the patients' suffering, they felt that they had failed. They feared that the patients' trust in them might have been lost or diminished, which threatened or hindered the development of a caring relationship. The practitioners experienced suffering when they were unable to alleviate that of the patients. They described it as powerlessness and wished for closer teamwork to enable them to inform the physician on duty about situations when a patient's suffering was experienced as overwhelming. Eriksson (2013) holds that ethics takes place here and now and that seeing and becoming aware means responsibility, which may involve informing the physician about the patient's situation or discussing problems at team coordination meetings. This involves witnessing and providing evidence (Eriksson, 2013), which is one meaning of responsibility.

Nurses and anesthetists underlined the importance of patients being able to rest and sleep when conscious during MVT, as it requires a great deal of energy. However, to rest/sleep, patients must feel secure, which presupposes trust in the professionals as well as the confidence that they can place their lives in the hands of the professionals. Løgstrup (1992) claims that human beings assume that fellow beings are kind and willing to do their best until otherwise proven, but being completely dependent on others may imply some kind of belief that "the other" will protect and do good. However, critically ill patients receiving MVT have no choice but to rely on the professionals. Therefore, the nurses' statements about the importance of being trustworthy and keeping the promise to do whatever they can to alleviate suffering reflect a caritative substance and an ethos of responsibility and human kindness. Morse (1997) found that patients only felt safe when they considered the staff competent and trustworthy. Patients who feel safe will accept assistance and submit to care. Nurses and anesthetists related that they could see patients withdrawing, which they interpreted to mean that the patients were tired and no longer had the strength to continue struggling for survival, saving their energy to merely endure the situation. This is in line with Morse (2001) and Morse, Beres, Spiers, Mayan, and Olson (2003), who described that when enduring, patients suppressed their emotions and did not show any facial or bodily movement.

Many physicians in particular expressed that caring for conscious patients receiving MVT diminished objectification of them. Instead, the conscious patient can be more involved in the care process, which nurses described as

inviting the patient to collaborate and working together for recovery. Pettersson, Melaniuk-Bose, and Edell-Gustafsson (2012) discussed the importance of collaboration between anesthetists, nurses, nursing assistants, and physiotherapists for treatment planning and patient support to maintain their confidence during weaning from MVT. The question is whether and to what degree patients and even their relatives can and should be involved in physicians' decisions about sedation and treatment regimens. Can patients become participants in the process and what influence should nurses have? Karlsson, Bergbom, and Forsberg (2012) found that patients can be partially involved in sedation decisions, some care decisions, and that they should be informed about what is going to happen.

Nurses expressed that caring for conscious patients during MVT requires a different approach compared with unconscious patients. They stated that it is important to remain by the bedside and be there to support the patient's recovery. According to Kasén (2002), when staff support patients, they mediate a caring relationship by which they show that patients are important to them and they want them to survive. This is in line with Karlsson, Bergbom, and Forsberg (2012) and Karlsson, Forsberg, and Bergbom (2012), who found that standing by the patient mediated caritative caring based on presence, attentiveness, and togetherness. However, the opposite was also found in this study, where physicians and nurses sometimes left patients alone with a bell because they wanted to provide independence and privacy.

The interview text was read separately several times by both authors and after each reading they met to discuss what had been understood, which gave rise to new questions. The understanding presented is based on the authors' pre-understanding including their theoretical perspective, thus a different perspective could have resulted in other themes and understandings. Quotations were used to illustrate the interpretations, so that the reader can judge whether they are reasonable. Gadamer (1989) stated that we should use our pre-understanding to comprehend new things and when we think that we understand we should question our understanding. There is a risk that the interviewer, an experienced nurse, may have been too quick in understanding what the participants told her and thus did not ask for further explanations and clarification. Despite the short duration of the interviews, the data were rich.

Three participants from the same ICU representing each professional category (anesthetists, nurses, and nursing assistants) were interviewed, thus a total of nine persons participated, which can be considered very few as well as not representative of all ICUs. However, these participants had long experience of working with and caring for unconscious and heavily sedated patients as well as conscious, non-sedated patients. It was agreed that it was

important that the participants could make comparisons between the two sedation strategies in relation to caring. There is a risk that those participants who experienced ethical dilemmas or found it difficult to care for these patients volunteered. However, some participants also stated that it was more challenging and inspiring to care for conscious patients as they could establish communication with them. The reason for choosing the ICU in question was the fact that it implemented a sedation regimen several years ago, where as many patients as possible are conscious during MVT. However, this constituted a limitation in terms of the intention of collecting data from different settings to obtain a wide variation in experiences. Lincoln and Guba (1985) claim that the degree of transferability is a direct function of the similarity between two contexts and that information about both contexts is necessary to judge transferability. We believe that the findings are transferable to other contexts in which physicians, nurses, and nursing assistants care for conscious patients during MVT.

Research that focuses on the effects of light or no sedation in relation to recovery is needed, as positive results of, for example, patients' health-related quality of life may influence and encourage staff to develop caring strategies. However, Strøm et al. (2011) investigated patients' quality of life by using the SF-36 after discharge from an ICU. One group was woken every day while the other did not receive any sedation during MVT. When comparing quality of life, no statistical differences were found between the groups.

The authors' understanding of the participants' statements was that caring for conscious patients during MVT was experienced as difficult, as some patients' suffering was so visible. Witnessing patients' suffering evoked distress among the professionals and a feeling of harming the patient. This was understood as unethical, especially if they were unable to ease the situation. Nurses felt especially responsible and believed that they had broken their promise to care for and protect the patients as well as to do their utmost to alleviate suffering. When caring for conscious patients, it takes time to adapt and find out how to act, as communication is difficult to establish. Actions were taken to relieve patients' suffering such as facilitating opportunities for sleep and rest as well as showing concern. Teamwork in addition to better communication and planning between physicians and nurses was suggested, as was a lower nurse–patient ratio to enable nurses to be attentive, encouraging, and close to the patient.

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