Proposals concerning maintaining the link between patients hospitalised for Covid-19 who are on life support and their loved ones

Version 1 - 27 March 2020

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Grounds

Patients remaining in hospital on life support is a psychologically complex situation for both patients themselves and their family members and loved ones. It is often traumatising, and even more so whenever a patient is in critical condition or at the end of their life (1). Occurrence rates for post-traumatic stress disorder (PTSD) in patients who have been hospitalised and are on life support have been estimated at between 14 and 41% for France (1), increasing to over 50% for cases involving a bereavement.

The classic factors associated with PTSD occurring are 1) a lack of understanding as well as information on why the patient has been hospitalised (2) and 2) the patient dying, which is often felt more intensely after taking the decision to limit their treatment (1). The quality of the relationship and communications between the team providing health care and the patient's loved ones during the mourning period is strongly linked to preventing symptoms of anxiety, depression and PTSD occurring in loved ones (3). Likewise loved ones being present whenever care is given - even for critical cases - has proved to be relevant in reducing the impact of the death of the patient on loved ones.

Obviously, the nature of the current SARS-CoV-2 pandemic makes patient visits incredibly difficult. The breaking off of the physical bond between patients and their loved ones is brutal, absolute and must be enforced for an extended period of time.
This is down to the following:

- The risk of loved ones or their carers being infected during in person visits
- Loved ones living in an area under lockdown, thereby limiting movement between their place of residence and the hospital
- The strict isolation requirements in place for patients
- Caregivers not having enough time to safely supervise visits.

Despite this however the lack of contact between patients and their loved ones has the following consequences:

- Loved ones' suffering increasing due to a complete lack of visual representation of the situation (place, caregivers) the patient is subjected to. The public at large most likely will have a very difficult time imagining what an intensive care room or service looks like - and whatever they do manage to imagine is undoubtedly more anxiety-inducing than the actual reality of things.
- Increased risk of PTSD in patients
- Increased risk of PTSD for loved ones
- Difficulties communicating with loved ones
- Possible difficulties in carers developing an empathetic link with the patient's loved ones
- Consequently, possible changes in ethical conditions under which major decisions are taken, such as limiting or stopping treatment.
- Not being able to obtain consent from loved ones so patients would be able to participate in clinical trials.

Principles

Despite the number of challenges intensive care services find themselves up against by their very nature, and furthermore despite those additional difficulties faced concerning loved ones visiting patients, the principles set out below should still be borne in mind.

1. Ensure keeping patients' loved ones informed remains a priority.
2. Efforts in this respect should entail updating loved ones on a daily basis, at the very least.
3. Loved ones should be able to be contacted by telephone, inasmuch as possible.
4. Information provided to families should ideally be the subject matter of a standardised protocol for the purposes of ensuring certain information is always given, as well as ensuring the best way of communicating said information.
5. In the event in person visits have been organised, loved ones should be properly protected against SARS-CoV-2 and in any event preventing visits from leading to people gathering around intensive care services.
6. Audio and video media may be used to facilitate communication between patients and their loved ones.
7. No images of a patient lying unconscious should be transmitted, as the patient cannot give their consent.

Examples of initiatives undertaken to promote communications with loved ones

Several initiatives have sprung up in a number of units in an attempt to circumvent difficulties faced in this respect. Below are descriptions of said initiatives. The end purpose here is not to recommend one approach over others but rather:

- Giving examples of actions which have already been implemented to remedy visits being prohibited.
- Supporting these initiatives and acting as a means for a future request for materials (audio/video devices, human resources, etc.) or approvals (entry into hospital, etc.).

Daily calls

A large number of services have implemented systems whereby a patient's care team systematically ring up the patient's loved ones. The models used here however vary widely one to the other. Calls can be made by senior doctors, in-house doctors, work experience students, individuals assigned solely to perform this specific task or by paramedical caregivers. Calls are made at the end of the morning shift in a number of services after the patient's prescription has been given.

Some services have implemented a dedicated telephone line so patients' family members can ring them up whenever they feel like it, oftentimes during fixed time slots. Those individuals dealing with patients are therefore dedicated to this task during these times.

In some units patients' loved ones are regularly contacted by a service psychologist. In certain specific cases these calls however are only made to the loved ones of patients who are in very critical condition or who have recently died.

Voice messages from loved ones

The driving principle here is enabling patient loved ones to record voice messages which will then be passed on to the patient by the care team.

- In places where this has been implemented an exclusive line and a smartphone have been set up to this end.
- Families can leave voice messages here (via answerphone or a WhatsApp-

style messaging service) for patients or send written texts (via SMS).
- The message is then played out or read aloud in the patient's room.
- The individuals responsible for performing this task are either volunteers or psychologists, who are more used to the emotional management this sort of scenario requires.

This method enables loved ones to let the patient know they are still there for them, symbolically contributing to their care and indirectly addressing them with messages of encouragement, hope and well wishes.

For dying patients these messages allow loved ones to symbolically be at the patient's besides, letting them say things they could not have possibly said prior to the patient's hospitalisation and allowing them to say their farewells, an essential part of the grieving process.

Virtual visits

Some units have implemented video visits. The materials used are smartphones and tablets. These visits are solely organised for conscious patients who are able to give their consent to letting their loved ones see them.

In person visits

In person visits are normally arranged for patients where any further deterioration of their condition would lead to concerns of their imminent death. In some units in person visits are organised systematically for all patients having undergone intubilation or who are on ventilators.

- Some services only limit in person visits to those patients who are on mechanical ventilation and who cannot communicate with their loved ones via telephone. Other services organise in person visits for all patients.
- The number of visits will be limited however, such as for example one visit per patient per day or every two days. The visitor will normally be the same person for the purposes of getting them used to any dressing/undressing procedures they may have to go through.
- The services who have implemented visits have reported that loved ones do not physically want to come to hospital out of fear of contamination, the stress involved in seeing their loved on in intensive care or because of difficulties actually making it to the hospital.
- A timetable of visits is normally implemented so all of the loved ones of the patients in intensive care do not all turn up at once. This helps limit contact between loved ones as well as makes accompanying them to see the patient easier to manage.
- Visitors are normally interviewed concerning their state of health either at service reception or via telephone. A visit log is likewise kept.
- Outside of the service loved ones are asked to change into the same PPE caregivers use in order to enter one of the rooms. Unit medical or paramedical caregivers will normally assist visitors with changing into the PPE. Specially trained volunteers may also help with this procedure.
- In some units the visiting loved ones are accompanied by a caregiver into the room with the patient, while others prefer not to have the caregiver in the room to limit their exposure. Furthermore, in other units loved ones are told to keep their distance from the patient to prevent contamination.

- Loved ones remaining outside of the room and observing the patient via a window is also an option. In this case they may not require full PPE, although they should be required to wear a surgical mask.
- After exiting the room loved ones are asked to remove all PPE with the assistance of a third party who should strictly follow all rules in place.
- The loved ones may be interviewed by team members (doctors, nurses, psychologists) before or after entering the patient's room.
- Loved ones should be issued documents they can show to law enforcement officials justifying their entry into hospital for those cases where only hospital staff are allowed entry. This may be in the form of a medical report.
- For unconscious patients some units have created scrapbooks which are given to the patient's family so all of their loved ones can contribute.

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