Clinical Note

Withdrawal of Ventilatory Support at Home on Hospice

Kenneth M. Unger, MD, FACP, FCCP, FAASM, FAAHPM Houston Program, Vitas Healthcare, Inc., Houston, Texas, USA

Abstract

Context. When ventilatory support is withdrawn in an intensive care unit (ICU), the place of death for most patients is the hospital. However, the majority of terminally ill patients prefer to die at home. Few articles have addressed taking adult mechanically ventilated patients home from the ICU for withdrawal of ventilatory support (WVS).

Objectives. To determine the outcomes of a protocol-driven program of WVS in the home under hospice care.

Methods. A retrospective chart review of 14 consecutive patients who had WVS at home. All subjects were mechanically ventilated ICU patients referred to hospice with a request for WVS to be performed in the patient's home. A protocol/checklist guided care. Medical records were reviewed to obtain demographic and medical information, particularly for duration of mechanical ventilation, the use of premedication, level of consciousness at the time of WVS, symptoms following WVS, pharmacologic measures used for symptom control after WVS, and survival time after WVS.

Results. At the time of WVS, five patients were awake or arousable and nine were stuporous or comatose. Ten patients required no medication before WVS; only four required medications for symptom control after WVS. Median survival after WVS was 18.15 hours. In all cases, symptomatic control was judged to be excellent.

Conclusion. Successful WVS and a natural death at home is possible with logistic support from the hospice organization and the expertise of the hospice team, guided by a comprehensive protocol/checklist. J Pain Symptom Manage 2016; ■:■-■. © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Hospice care, place of death, withdrawing treatment, end-of-life care, palliative care

Introduction

It has become common for ventilatory support to be withdrawn from terminally ill, ventilator-dependent patients to allow a natural death. Most patients who die in intensive care units (ICUs) are managed by withholding/withdrawing life-sustaining treatments (LSTs). Although the preferred place of death for the majority of terminally ill patients is home, he he place of death for most of these patients is the ICU. When an ICU patient requests that withdrawal of ventilatory support (WVS) be performed at home, there are potential ethical, legal, logistic, and clinical challenges because of the uncommon nature of this situation. The barriers are so great that a home death is often not possible.

Few articles address taking adults home from an ICU for WVS.^{10–13} In these reports, patients were taken home by ad hoc teams of facility staff (nurses and/or physicians). If the patient survived WVS, care was transferred to a general practitioner, supported by community health services, ¹² hospice, ¹¹ or a palliative care practitioner. ¹⁰ We report on the results of a protocol-driven program of WVS performed in the patient's home by a hospice team.

Methods

This report describes a retrospective chart review of 14 consecutive patients who had WVS at home. A protocol was developed to guide care, based on principles

Address correspondence to: Kenneth M. Unger, MD, FACP, FCCP, FAASM, FAAHPM, Houston Program, Vitas Healthcare, Inc., 4327 Silverwood Drive, Houston, TX 77035, USA. E-mail: LungMD01@gmail.com

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laid out by Rubenfeld, ¹⁴ Sine, ¹⁵ and von Gunten. ¹⁶ The protocol consisted of a checklist of tasks, each assigned to a specific member of the hospice team (Table 1).

These patients had been admitted to local hospitals with an acute illness and had required intubation. When the ICU clinicians deemed likelihood of successful extubation low, they recommended WVS. Because of patient or family requests to have WVS performed at home, they were referred to hospice. Between February 2009 and October 2013, 14 patients were transferred to hospice care and transported home for WVS. Patients admitted to the hospice inpatient unit for WVS or patients who were chronically ventilated at home were excluded from this report.

After receiving a request for WVS at home, we addressed the goals of care and concerns of all stakeholders to ensure that there was consensus. It was communicated clearly that if significant conflict or

persistent indecision about WVS arose after the patient arrived at home, the patient would be discharged from hospice care and returned to the hospital. The hospice social worker consulted with the family and assisted with funeral arrangements. Intravenous (IV) access was left in place at time of discharge. The protocol required that medication, supplies, and durable medical equipment were in place at the home before the patient left the hospital. An ambulance supplied the ventilator, set in assist-control mode, during transportation and until WVS.

The hospice team (a nurse case manager, a chaplain, a continuous care nurse, and a physician) assembled in the home before the patient arrived, prepared the patient's bed, and verified that the appropriate equipment and medications had been delivered. When the patient arrived home, they were stabilized and made comfortable by the nurses. The physician performed a physical examination, which included a trial of spontaneous breathing.

Table 1 Withdrawal of Ventilatory Support Protocol/Checklist

- At the time of initial contact and evaluation (AN):
- o Confirm that WVS soon after arriving home is consistent with the patient's/family's goals of care.
- o Assure that the concerns of all the stakeholders have been addressed and that consensus has been reached.
- Ensure that they understand that if there is conflict that cannot be quickly resolved, the patient will be immediately returned to the hospital.
- o Document the discussion of WVS in the hospice chart, with date, time, and a list of who was present.
- o If the patient is Catholic, has he/she received the Sacrament of the Ill?
- Transmit medical records to the hospice physician
- Before discharge
 - o The Out-of-Hospital DNR is signed (AN).
 - IV access: ensure that IV access is not removed before transfer (AN).
- o Medications are profiled (AN).
- The ambulance company has been contacted, has a ventilator available, and agree with the plan of care (AN).
- o Make sure that there are grounded plugs in the home. If not, notify the medical director (AN).
- o Arrange for continuous care (TM).
- Help the family make funeral arrangements (SW).
- o Obtain contact information for the physicians who should receive follow-up (AN).
- o Arrange for a team nurse, the chaplain, the physician, and the continuous care nurse to be in the home when the patient arrives (TM).
- o The following must be in the home before patient discharge (AN):
 - Suction: Suction machine, In-line suction catheter, Tonsil-tip suction catheter
 - Oxygen: concentrator, nasal cannula, simple oxygen mask, or trach collar
 - Medications & supplies
 - Atropine ophthalmic drops, 1%
 - Morphine sulfate oral solution, 20 mg/mL, 30 mL
 - Lorazepam oral solution, 2 mg/mL, 30 mL
 - Injectable morphine, 5 syringes with 5 mg morphine
 - Injectable lorazepam, 2 mg/mL, 3 1 mL vials
 - Sterile syringes, $10 \text{ mL} \times 2$, $1 \text{ mL} \times 2$
 - Grounded electrical power strip (if needed)
- At home, before WVS
 - o Perform history and physical examination with trial of spontaneous breathing (MD).
 - Discuss possible outcomes, including the possibility that death may not occur immediately, as the patient might resume spontaneous breathing (MD).
 - o Decide who is going to be at the bedside at time of WVS (MD & Chaplain).
 - o Decide if there any special prayers to be said or rituals to be observed (Chaplain).
- o Offer a prayer at bedside (Chaplain).

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