

Original Article

Descriptions by General Practitioners and Nurses of Their Collaboration in Continuous Sedation Until Death at Home: In-Depth Qualitative Interviews in Three European Countries

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Abstract

Context. One palliative care approach that is increasingly being used at home for relieving intolerable suffering in terminally ill patients is continuous sedation until death. Its provision requires a multidisciplinary team approach, with adequate collaboration and communication. However, it is unknown how general practitioners (GPs) and home care nurses experience being involved in the use of sedation at home.

Objectives. To present case-based GP and nurse descriptions of their collaboration, roles, and responsibilities during the process of continuous sedation until death at home in Belgium, The Netherlands, and the U.K.

Methods. We held in-depth qualitative interviews with 25 GPs and 26 nurses closely involved in the care of 29 adult cancer patients who received continuous sedation until death at home.

Results. We found that, in Belgium and The Netherlands, it was the GP who typically made the final decision to use sedation, whereas in the U.K., it was predominantly the nurse who both encouraged the GP to prescribe anticipatory medication and decided when to use the prescription. Nurses in the three countries reported that they commonly perform and monitor sedation in the absence of the GP, which they reported to experience as “emotionally burdensome.”

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Accepted for publication: May 6, 2014.

Conclusion. We found variety among the countries studied regarding the decision making and provision of continuous sedation until death at home. These differences, among others, may be the result of different organizational contexts in the three countries such as the use of anticipatory medication in the U.K. *J Pain Symptom Manage* 2015;49:98–109. © 2015 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

Key Words

Palliative sedation, continuous sedation until death, general practitioners, nurses, collaboration, home

Introduction

Continuous sedation until death (from here onward referred to as sedation) is often used as a last resort option for relieving intolerable refractory (i.e., untreatable) symptoms of terminally ill patients in which the patient's consciousness is lowered until the time of death.^{1–4} Previous international research has shown that sedation is commonly used in different countries and that systematic differences occur in its practice among countries.^{5–8} Guidelines on sedation were developed in The Netherlands in 2005 and in Belgium in 2010.^{2,3} In 2009, the European Association for Palliative Care (EAPC) published a framework of recommendations for the use of sedation.⁴ No sedation guidelines exist in the U.K.

Although these guidelines have been primarily developed for supporting physicians in their practice of sedation, recommendations also may have consequences for tasks performed by nurses involved in the care for the patient.⁹ Thus, guidelines recommend that GPs should bear final responsibility for the performance of sedation, but studies have shown that nurses are also important participants in the decision-making process and the implementation of sedation.^{2–4} As palliative care requires a team approach according to the World Health Organization,¹⁰ it is surprising that studies have been either focused on physicians' or nurses' practices and attitudes regarding the complex realities of the performance of sedation, and have not studied these issues in-depth from a double perspective.

For instance, a British study suggested that U.K. nurses have a key role in activating

anticipatory prescriptions, although research into this issue is scarce.¹¹ In the U.K., these anticipatory prescriptions are written by the GPs for patients who wish to remain at home in the last few days or weeks to ensure that there is no delay in responding to a symptom if it occurs.¹² The anticipatory medication that is prescribed in advance consists of sedatives alongside other commonly used drugs at the end of life. These are often referred to as the "just in case" medications and are kept in the patient's home.¹³

Furthermore, recent Belgian and Dutch studies found that home care nurses were less often involved by GPs in the decision-making process of sedation than nurses working in institutions.^{9,14–16} However, they were frequently involved in the performance and monitoring of sedation at home in the absence of the GP in a substantial number of cases.^{9,14,15} Another substantial number of Dutch nurses made independent decisions concerning the dosage of medication.¹⁴ The authors of these studies, therefore, have raised questions regarding the autonomy and responsibilities of nurses at home, and their collaboration with the GPs during sedation.^{9,14,15}

Especially in the home care setting, the practice of sedation can be challenging for the GPs and the nurses.^{17–20} Barriers surrounding the adequate performance of this practice at home as experienced by the GPs and nurses include a lack of knowledge of GPs about this practice; obstacles regarding the availability of medications, medical equipment, and clinical staff at all times; and a lack of time, coordination of the patient's care at home,

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