

Use of Oxygen at the End of Life: Attitudes, Beliefs, and Practices in Wisconsin

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ABSTRACT

Introduction: Oxygen therapy for the management of breathlessness remains controversial and little information is available regarding the practice of using oxygen at end of life. Oxygen use in end-of-life care is increasingly being questioned, while the use of oxygen for routine “comfort care” at end of life continues.

Objective: The purpose of this study was to investigate the use of oxygen at the end of life and to understand its role in contemporary palliative care practice.

Methods: The project involved a survey to learn about medical facility practices regarding the use of oxygen at the end of life and attitudes and beliefs regarding these practices, specifically the opinion of whether or not oxygen prolongs the dying process at the end of life. Questionnaires were mailed to 42 directors, coordinators, or managers of palliative care services in hospitals throughout Wisconsin. Twenty-five surveys were returned for a response rate of 59.5%.

Results: Forty-three percent of respondents believed that oxygen use at the very end of life affects the timeline of natural death by prolonging the dying process. Ninety-six percent of the respondents’ facilities had a standard “comfort care” protocol for end-of-life patients that offered oxygen, regardless of whether patients had breathlessness or not. Respondents cited reasons that staff might use oxygen for these patients: patient comfort, family request, emotional comfort of family, prolongation of life when that was a patient goal, emotional comfort of staff. Respondents also cited reasons that staff might not use oxygen for these patients: oxygen did not seem to bring comfort, oxygen was an irritant to patient, prolongation of natural death was not a patient/family goal, oxygen use did not add to the emotional comfort of patient/family/staff.

Conclusion: Current practice on oxygen use in palliative care was identified and the information helps to determine how decisions are made regarding oxygen use. The research adds to palliative care practice knowledge and supports continuing research and dialogue on practice issues.

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INTRODUCTION

It is relevant to study the dying timeline for patients who are receiving comfort care and to look at what might potentially delay the natural timing of dying. Patients at end of life often wish for a death without any measures to prolong life beyond the natural time of death. The extension of dying time may be especially impactful for patients who are experiencing end of life in a hospital setting. Family members can become exhausted from a prolonged vigil at the bedside. Fragile patients on comfort care who do not die within an allotted time-frame (usually several days) might be transferred away from the hospital to complete their dying process in another facility. In these cases, there can be a physical, emotional, and financial toll for patients and families. Patient and family goals should dictate what measures are used or not used during this time, and survey research can stimulate dialogue and further exploration to understand the benefit and burdens of the measures offered.

Dyspnea—shortness of breath—is one of the most distressing and prevalent symptoms for patients at the end of life. It is also profoundly distressing for caregivers and health professionals who witness it.¹ Dyspnea is a “complex subjective experience” that is common in terminal illness, and it includes physical, psychological, social and spiritual components, and it is important to recognize how each of these contributes to the total suffering of dyspnea.² The management of terminal dyspnea involves both pharmacological and nonpharmacological treatment, with the main pharmacological palliative treatments being oxygen and opioids.^{2(p327)}

Oxygen therapy for the management of breathlessness remains controversial, and little information is available regarding the practice of using oxygen at end of life. In a published literature review, that served as a basis for this introductory survey research of palliative care coordinators, the use of oxygen in end-of-life care was questioned by cited authors, and growing evidence suggests that oxygen use may not always be indicated³ and may be unbeneficial⁴ and unnecessary⁵ at the end of life. In addition, some professionals have postulated that oxygen use at the very end of life may prolong the dying process^{6,7} and have questioned whether oxygen is needed for routine care for patients or for easing family member anxiety.⁸ Further, more definitive research is necessary, but gaining information on this topic is important. The purpose of this survey research was to investigate the use of oxygen at the end of life and to understand its role in contemporary palliative care practice. The project involved learning about palliative care practices in hospital settings regarding the use of oxygen for patients at the very end of life as well as attitudes and beliefs regarding these practices.

Literature Review

The literature indicates a need for further research on the topic of oxygen use at end of life.^{3(p372)} In a prior published review, the authors found no studies that looked at the question of interest: “Does oxygen at very end of life prolong the dying process?” However, there were studies that addressed some surrounding issues. The research studies found in the literature review were grouped into 3 questions that were subsequently used to devise the survey tool for this research project: “Does oxygen help alleviate breathlessness?”, “What other options are available to alleviate breathlessness?”, and “How do patients and families feel about the use of oxygen?” Each question is summarized briefly below.

Does Oxygen Help Alleviate Breathlessness?

Oxygen should not be given solely based on “intuitive assumption of benefit.”⁹ Yet, oxygen is commonly used to treat breathlessness in advanced disease, although there is no evidence that it is effective^{10,11} and its place in palliative care remains controversial.¹² It is often given on a “compassionate basis,” since many palliative care patients are otherwise not eligible for oxygen therapy.^{5(p989)}

Breathlessness, subjective sensation of inability to catch one’s breath or an uncomfortable awareness of breathing, is a common symptom at the end of life with reported prevalence of 21% to 70%.¹³ Although the majority of patients with dyspnea do not have demonstrated hypoxemia, those who do have low oxygen saturation may benefit from oxygen.^{13(p380)} However, oxygen effectiveness for alleviation of breathlessness in nonhypoxemic patients is minimal.^{5(p991),14} Undesirable consequences of oxygen use include high cost, discomfort, airway damage, and prolongation of

the dying process in patients who are ready to accept the natural timing of death.^{7(p1030)} One study found that physicians have not reached consensus regarding prescription and benefits of home oxygen for palliative cancer patients, and this is likely due to a lack of evidence since it is challenging to apply an evidence-based approach in palliative care.¹⁵ Mixed results have been recorded on patients with breathlessness prescribed oxygen therapy versus room air.¹⁶ Several studies found little benefit from oxygen when the patient has nonhypoxemic dyspnea.^{12,14}

What Other Options Are Available to Relieve Breathlessness?

The literature review identified that less burdensome strategies should be considered after brief assessment of the effect of oxygen therapy on the individual patient.^{12(p790-791)} One systematic review and meta-analysis demonstrated a statistically significant effect of oral and parenteral opioids on the sensation of breathlessness.¹⁷ Another trial yielded similar results in that patients receiving morphine had a significant decrease in breathlessness without depression of respiratory rate, sedation, or obtundation.¹⁸ In another study, opioids worked significantly better than oxygen in reducing the intensity of dyspnea even in hypoxic patients.^{9(p375)} Since breathlessness is related to anxiety, benzodiazepines or anxiolytic drugs have been widely used to reduce the sensation of breathlessness even though evidence regarding their effectiveness is unclear.¹⁹

There needs to be more research into the role of nonpharmacological measures. Alternatives include increasing air circulation, breathing training, repositioning, and utilizing relaxation practices; these can provide simple and practical ways to reduce breathlessness without serious side effects. Attention to the patient’s psychosocial status can decrease breathlessness. Dyspnea may be “a significant component of the quality-of-life experience,” and addressing coping strategies that target anxiety and depression for patients at the end of life can enhance the overall quality of life.²⁰

How Do Patients and Families Feel About the Use of Oxygen?

Dyspnea is a very frightening experience for the patient at the end of life. The authors’ review of literature found that current studies on patient and family perception of oxygen use pertained to patients who were not at end of life. These patients who were earlier in their disease process identified more advantages than disadvantages to using oxygen, including improvement of shortness of breath, nausea, appetite, and skin color.²¹

Furthermore, when clinicians were asked about why they prescribed palliative oxygen, a common reason was patient or family request.²² Even if oxygen was not clinically indicated, it is sometimes easier to initiate oxygen to “treat the caregiver’s anxiety.”^{22(p270)} Breathlessness creates significant suffering both for patients and for caregivers, and this often creates a feeling of

helplessness in the conscious patient as well as for families and friends and also the clinicians trying to provide relief.²³(p932) In the last hours and days of life, caregiver stress may predominate over patient distress in assessing levels of breathlessness, especially if patients are unable to participate in the ranking of their symptoms due to reduced levels of consciousness.²⁴ Palliative oxygen is also sometimes prescribed simply to “do something.”⁴(p522)

One qualitative study looked at nurses’ and patients’ perspectives on oxygen therapy.²⁵ Device comfort was the most common factor raised by patients. Patients also commented that at times their ability to talk, eat, and drink was restricted while receiving oxygen therapy. However, despite their concerns, all patients interviewed considered low flow oxygen to be effective.

METHODS

Although patients at end of life can be found in many settings (hospital, skilled nursing facility, home/hospice, community-based residential facility, assisted living facility), a decision was made to narrow the focus of this study to practices and beliefs surrounding use of oxygen for hospitalized patients. Keeping in mind the area of interest, the target audience became health care professionals who cared for end-of-life patients in a hospital setting. Inpatient palliative care professionals were presumed to have knowledge of the end-of-life practices and beliefs in their own hospitals. Forty-two inpatient palliative care services were identified throughout Wisconsin. The director/coordinator/manager of these programs was thought to be the best access to the needed information, and a survey study that included a 13-question questionnaire was sent to each.

Purposive sampling was utilized for this study. Using purposive sampling for this exploratory study allowed the researchers to focus on particular characteristics of the population of interest, best enabling the authors to answer the research questions. The institutional review board at the university at which the lead author works formally reviewed and approved this study. A cover letter explaining the study and informed consent was provided to potential participants, which stated that informed consent is implied upon completion of the survey. Participants were encouraged to ask any questions before they participated.

Survey

The survey questions were based on the literature research questions and were expanded upon through author discussion and consultation with end-of-life clinicians. The major survey research questions were: “Does oxygen help alleviate breathlessness?”; “What other options are available to alleviate breathlessness?”; and “How do patients and families feel about the use of oxygen?” The question that emerged through the literature review and through discussions with clinicians is “Does oxygen at the very end prolong the dying process?” Therefore, questions about the percep-

tions of the use of oxygen were included in the survey. We asked the respondents to answer based on patients who are “within days of their expected death and who will most likely be staying at your facility until time of death.”

Research Question-Survey Question Example

Regarding the question of whether oxygen helps alleviate breathlessness, the survey asked, “What are the reasons your facility might use oxygen for “comfort care” patients who are within days of their expected death and who will most likely be staying at your facility until time of death?”

Related to the question of what other options are available to alleviate breathlessness, 1 survey question asked, “Other than oxygen, what practices or care are commonly used at your facility at the end of life to achieve respiratory comfort?”

Related to the question of how patients and families feel about the use of oxygen, the survey asked, “What thoughts/concerns have family members shared about oxygen use?” and “Have you ever put oxygen on a patient to please a family?”

Related to the question of whether oxygen at the very end prolongs the dying process, 1 survey question asked, “In your experience or opinion, do you personally believe oxygen affects the timeline of the dying process?”

Process

Questionnaires were mailed to 42 directors, coordinators, or managers of palliative care services in hospitals throughout Wisconsin. Twenty-five surveys were returned for a response rate of 59.5%. The survey asked a series of questions referring to oxygen use at the end of life, the standard practices of the hospital, and also ascertained demographic information. Participants completed a 13-question survey with both closed- and open-ended questions. Participants were sent a cover letter and hard copy of the survey through the mail. Then, 1 to 2 weeks later, they were sent an email cover letter and survey link in order to increase participation. Participants were given the instructions twice to only complete 1 survey – either the email or the hard copy survey. Subjects who completed the online survey did so utilizing the Qualtrics online survey program. Subjects who completed the survey on paper mailed back their surveys; their surveys were then entered into Qualtrics. All survey responses were anonymous.

Demographics

Of the 25 directors/coordinators/managers of hospital-based palliative care services who responded to the survey, all were health care professionals: physicians with specialty fellowships in palliative care (2), registered nurses with advanced degrees (15), and registered nurses (8). All had worked in palliative care for at least 2 years, with several working 10 to 20 years in the field. The average

age of respondents was mid-forties, with the youngest at 30 and the oldest at 64.

Significant diversity was found in regard to the environments in which they provided palliative care services. Fifty-five percent of the respondents practiced in an urban area (defined as a population of 50,000 or more), 25% practiced in a rural area (population of less than 2,500), and 15% were suburban (population of 2,500 to 49,999). Thirty-five percent of participants practiced in a community-based hospital and 10% were in an academic or teaching hospital. The total number of overall hospital beds ranged from 18 to 700. Many facilities had no designated beds dedicated to palliative care, noting that palliative care patients can go into any hospital bed. Those that had dedicated palliative care beds had anywhere from 4 to 15 beds. The number of palliative care patients served per year ranged from 10 to 1,600. Fifty-two percent of the palliative care services have a palliative care physician involved in the day-to-day management of patient care. Most programs only had 1 to 2 total full-time equivalent employees.

Data Analysis

Data analysis included a mixed methods approach. Quantitative data were entered into the statistical software program SPSS for analysis. Descriptive statistics were performed on demographic data. Responses to the open-ended survey data were coded and categorized into thematic categories. Qualitative responses were analyzed through content analysis. Responses Constant comparison was utilized until identified patterns and themes emerged. NVivo statistical software program supported the qualitative coding process.

RESULTS

Does Oxygen Help Alleviate Breathlessness and Does Oxygen at the Very End Prolong the Dying Process?

Data analysis was conducted to determine respondents' perspectives on the use of oxygen at the end of life within the context of their hospital's standard of practice. Forty-three percent of respondents believe oxygen use affects the timeline of the dying process; 100% of those respondents also believe that oxygen use prolongs the dying process. Ninety-six percent of the respondents' facilities have a standard "comfort care" protocol or order set for patients who are within a few days of their expected death and who will most likely be staying at their facility until time of death. The majority of respondents have oxygen as part of the standard order set for patients at the end of life, regardless of whether patients have symptoms of breathlessness or not. One participant commented "nobody thinks to take it [oxygen] off when the goals change."

Respondents cited the following reasons their facility used oxygen for "comfort care" of patients who are within days of their expected death: increased physical comfort of patient (71%), fam-

ily requests oxygen (63%), increased emotional comfort of family (63%), patient's goal is to prolong life (29%), makes the staff feel as though they can at least offer something (25%), increased emotional comfort of staff (25%), other (including emotional support of patient) (21%). In terms of why a facility might not use oxygen for "comfort care" patients who are within a few days of their expected death, the following reasons were cited: does not seem to add to patient's physical comfort (83%), oxygen is an irritant (78%), seems to prolong the dying process, which is not the patient and/or family goal (61%), does not seem to add to the emotional comfort of the patient (61%), does not seem to add to the emotional comfort of the family (35%), does not seem to add to the emotional comfort of staff (26%), and other (1.4%).

In terms of why oxygen is utilized for patients at the end of life, respondents cited a variety of examples of how they have found this procedure helpful. A respondent stated, "We also use it for emotional comfort of the patient. If oxygen was used prior to comfort care, we typically do not immediately remove it unless we have the conversation with the patient/family." Another respondent stated, "We keep oxygen on when the patient goal is to prolong life (eg, waiting for family to arrive to say goodbye)."

What Other Options Are Available to Alleviate Breathlessness?

Results indicated that many facilities use alternatives to providing oxygen at end of life, including medications (95%), repositioning (90%), increasing air circulation (86%), spiritual practices (81%), breathing exercises (38%), music therapy (17%), aromatherapy (14%), massage therapy (10%), relaxation exercises (10%), and cognitive-behavioral therapy (10%). None of the facilities utilized acupuncture/acupuncture. The medications utilized were opioids (85%—with morphine being the most common), benzodiazepines (75%—with lorazepam being the most common), and anticholinergics (30%).

How Do Patients and Families Feel About the Use of Oxygen?

Eighty-two percent of respondents have put oxygen on a patient to please a patient's family member; many of these respondents indicated that this was for the emotional support of the family members and to feel like they were "doing something" as opposed to actually decreasing patients' symptoms of breathlessness. Several respondents explained they provide the family with further explanation regarding the role of oxygen as well as potential benefits and complications.

Many respondents cited the views of the patient and their family as significant factors in determining whether or not oxygen was utilized at the end of life, which is supported by the literature. A respondent shared, "They want to feel like they and we are doing something for their loved one. They think the patient will suffer or suffocate without it." Numerous respondents also cited family

members' desire for a peaceful death for their loved one and their concern that their loved one would be "gasping for air" during the final moments of life. Several also expressed having ongoing conversations with the patient's family in determining the appropriateness of the use of oxygen. A respondent shared, "We tend to treat families as extensions of patients and often will place oxygen for their comfort—at least initially. If providing oxygen becomes a discomfort to a patient or serves to prolong the dying process, then we continue to address this with the family." Another respondent stated, "I will typically provide information on the benefits/burdens of supplemental oxygen and allow families control of this, especially if it seems they need this."

DISCUSSION

Many hospitals use oxygen at the end of life and their reasons vary. Through this study, the attitudes and practices of inpatient palliative care directors/coordinators/managers in Wisconsin were examined to gain a contemporary image of the use of oxygen in hospital-based palliative care practice. It was determined there is a divergence of opinion among the respondents in regard to whether oxygen impacts the timeline of the dying process. Fifty-seven percent reported they do not believe it impacts the process, while 43% of respondents not only believe the use of oxygen does impact the dying process, they also believe it prolongs the process. Further, nearly all of the respondents who indicated oxygen use prolonged the timeline of the dying process reported oxygen use was especially impactful in prolonging the dying process when a patient was experiencing hypoxia. One respondent stated, "If a patient is hypoxic or having a respiratory death, it often does (prolong the dying process). But if it is a nonrespiratory death—there is none or minimum influence." These findings warrant further examination into the impact of the use of oxygen on the timeline of the dying process in respiratory versus nonrespiratory deaths.

It is also intriguing to consider that 100% of the facilities that have a standardized "comfort care" protocol for patients have oxygen available for patient use in the order set. A respondent stated, "Nobody thinks to take it (oxygen) off when the goals change." This raises the question of whether oxygen use is a routine element of comfort care rather than an option that necessitates individual assessment before it is used.

Our results also strongly emphasized the influence of the family in determining whether oxygen was used at the end of life. Numerous respondents indicated the importance of having this as an ongoing topic of discussion with the patient's family. This suggests that attaining a delicate balance between assessing the particular patient's situation, providing education to the patient's family, and supporting the wishes and well-being of all involved may be important.

Ultimately, our results suggested that these palliative care

respondents have a divergence of views in regard to the use of oxygen at the end of life. Some perceived that oxygen use may affect the timing of a natural death and posed that this frequently used approach be more of an individualized practice at the end of life – based on patient/family goals and involving education and support. More definitive research is necessary and there are many avenues of further research, but research suggestions include additional distribution of regional and national surveys detailing the attitudes and beliefs of health care professionals, patients, and family members related to oxygen use at end of life. Providers who care for end-of-life patients in nonhospital settings (skilled nursing facilities, home, hospice facility, etc.) should be surveyed. Other research suggestions include examining the physiological nature of the use of oxygen at the end of life and exploring education for families on the use of oxygen (how best to educate, family reactions to education and whether oxygen use is modified through education and discussion). Hopefully, this introductory research will encourage a continuing dialogue on end-of-life care and continuing research that supports optimum care for patients and families.

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