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# The Clinical and Social Dimensions of Prescribing Palliative Home Oxygen for Refractory Dyspnea

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## Abstract

**Background:** Chronic breathlessness is a significant problem in palliative care and oxygen is often prescribed in an attempt to ameliorate it. Often, this prescription falls outside the current funding guidelines for long-term home oxygen use. The aim of this qualitative study was to understand the factors that most influence Australian specialist palliative care nurses' initiation of home oxygen for their patients.

**Methods:** A series of focus groups were held across three states in Australia in 2011 involving specialist palliative care nurses. The invitation to the nurses was sent by e-mail through their national association. Recorded and transcribed data were coded for themes and subthemes. A summary, which included quotes, was provided to participants to confirm.

**Results:** Fifty-one experienced palliative care nurses participated in seven focus groups held in three capital cities. Two major themes were identified: 1) logistic/health service issues (not reported in this paper as specific to the Australian context) involving the local context of prescribing and, 2) clinical care issues that involved assessing the patient's need for home oxygen and ongoing monitoring concerns.

Palliative care nurses involved in initiating or prescribing oxygen often reported using oxygen as a second-line treatment after other interventions had been trialed and these had not provided sufficient symptomatic benefit. Safety issues were a universal concern and a person living alone did not emerge as a specific issue among the nurses interviewed.

**Conclusion:** The role of oxygen is currently seen as a second-line therapy in refractory dyspnea by specialist palliative care nurses.

## Introduction

CHRONIC BREATHLESSNESS is a significant symptomatic problem across the community, with the frequently encountered social determinants of health such as lower socioeconomic status associated with higher prevalence.<sup>1,2,3</sup> In the setting of progressive life-limiting illnesses, even in the absence of apparent cardiorespiratory disease, both prevalence and intensity of breathlessness increase as death approaches.<sup>4</sup>

The rationale for provision of, and funding for, long-term home oxygen therapy is derived from two studies that have demonstrated a clinically significant survival advantage for the use of home oxygen by people with severe hypoxemia and chronic obstructive pulmonary disease (COPD).<sup>5,6</sup> The individuals who derived survival advantage had a PaO<sub>2</sub>

<55 mmHg or <60 mmHg and evidence of secondary sequelae of long-term hypoxemia.

Clinically, home oxygen is widely prescribed for refractory breathlessness and prescribing frequently falls outside of the current funding guidelines, especially in community settings where people are breathless despite normal or nearly normal blood oxygen levels.<sup>7-9</sup> Two recent systematic reviews and a multinational randomized controlled trial (RCT) have helped to define the role of oxygen prescribed for relief of symptomatic breathlessness when the criteria for long-term oxygen therapy are not met.<sup>10-12</sup>

Yet, oxygen use is not without adverse effects, with patients reporting physical and emotional impacts of having their mobility and autonomy compromised by a perceived reliance on home oxygen. Patients define the net clinical effect for them

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personally with great care.<sup>12,13</sup> Despite many people with breathlessness deriving little symptomatic benefit from it in the palliative setting,<sup>13,14</sup> there is a subgroup that is clear about the benefits derived from palliative oxygen.<sup>15</sup>

Although there is a dearth of information on prescribing home oxygen outside current international funding guidelines, it is widely acknowledged that this therapy is frequently ordered for people with breathlessness and advanced, life-limiting illnesses irrespective of oxygenation.<sup>8</sup> In Australia, specialist palliative care nurses can initiate or recommend a home oxygen prescription be sought from a specialist palliative care or respiratory physician or authorized general practitioner. Little is understood about the reasons underlying palliative care nurses' role in initiating a home oxygen order, although there appears to be variations in practice not explained by the underlying etiologies or the use of inpatient health services.<sup>16</sup>

The aim of this study is to understand the factors that guide Australian specialist palliative care nurses' initiation of palliative home oxygen, using the current international funding guidelines as a reference point.<sup>9,17,18</sup> Understanding why palliative care nurses initiate home oxygen prescriptions and the threshold for doing so is important if equitable, needs-based care is to underpin the symptomatic treatment of breathlessness.

## Methods

Seven focus groups were held with specialist palliative care nurses across three Australian capital cities: Sydney ( $n=2$ ), Adelaide ( $n=3$ ) and Perth ( $n=2$ ) during the second half of 2011.

## Approach

Given the paucity of data on the clinical decisions informing the initiation and prescription of home oxygen outside currently funded guidelines, a qualitative design using symbolic interactionism as a theoretical framework was chosen to explore the specialist nurses role in this process.<sup>19</sup> Adopting this framework helped explain participants' interactions with other clinicians and provided valuable insights into various institutional and administrative practices.

## Setting and sampling strategy

A purposive sample of specialist palliative care nurses with a minimum of 2 years clinical experience in this specialty was sought by inviting all members of the National Australian Palliative Care Nursing Society to participate in a focus group during June–August 2011. Snowball sampling was used to recruit additional participants. All of the focus groups were conducted in conveniently located meeting rooms in either the clinical setting or at a hired venue.

## Data collection techniques

A question route developed in consultation with clinical experts reflected the study aim and guided the focus group discussions (Table 1). These questions facilitated the exploration of specialist palliative care nurses practices in relationship to: managing home oxygen requests, prescribing thresholds, and addressing safety concerns (Table 1). The moderator (KB) led all of the focus group discussions. Other

TABLE 1. FOCUS GROUP QUESTION ROUTE

### *Focus group question route*

1. In your setting, who initiates the referrals for home oxygen?
2. In what circumstances would you prescribe/initiate home oxygen?
3. In what situations would you not prescribe/initiate home oxygen?
4. What factors do you take into consideration (safety concerns, risks, etc.) when prescribing home oxygen?
5. How much pressure do you get from carers to provide home oxygen?
6. For those people who do not qualify for home oxygen (not chronically hypoxic or desaturates during exercise), what do you do about the cost?
7. If a person lives alone, what concerns might you have about prescribing home oxygen?

*This last question will only be asked at the end of the interview.*

### *Demographic information*

1. To what discipline do you belong?
2. How many years have you been in practice?
3. Postcode of practice?
4. Number of times in the last year that oxygen has been prescribed/initiated for the home?
5. Number of times in the past year that oxygen has been prescribed for people who do not qualify for home oxygen?

members of the research team (JP, JS, and CG) shared the co-moderator role of scribe and observer. Each focus group lasted at least one hour and all were audiotaped with participants' permission and professionally transcribed verbatim.

## Analysis

Data collection and analysis were undertaken concurrently as reflexive activities.<sup>20</sup> The moderator and co-moderator reflected immediately on each groups' interactions and noted emerging themes. The focus groups continued until there was consensus within the team that no new content was being introduced. Two researchers (KB, JP) reviewed the transcripts for accuracy and re-read the content multiple times. The software program NVivo version 9, 2010 (QSR International, Doncaster, Victoria, Australia) was used to manage the data. A list of codes was generated using the interview questions as a guide. The team discussed the emerging themes, selected typical quotes, and preserved their context.<sup>21</sup> All necessary revisions were made prior to feeding the thematic summary and quotes back to participants for confirmation. The COREQ checklist (consolidated criteria for reporting qualitative research) has guided the reporting of these qualitative data,<sup>22</sup> ensuring attention to: clarification and justification, procedural rigor, representativeness, interpretive rigor, reflexivity and evaluation rigor, and transferability.<sup>23</sup>

The study received ethical approval from Flinders University's Social and Behavioural Ethics Committee. All participants provided written informed consent before focus group participation, along with demographic details, information about their oxygen prescribing practices over the past year, and their palliative care experience.

## Results

Fifty-one specialist palliative care nurses participated in the seven focus groups. The majority of this cohort worked in metropolitan community-based palliative care services ( $n=43$ ); the remainder worked in rural or remote settings ( $n=8$ ). Four of the nurses were male. On average, these participants had been working in specialist palliative care for 12 years (range 2 to 32 years). In the last 12 months, they had prescribed oxygen approximately nine times (mean, range 0 to 100), and estimated that only three patients (median, range 0 to 15) had been prescribed home oxygen outside of the current guidelines.<sup>21</sup>

## Themes

Two major themes emerged, each with two subthemes: 1) logistic health service issues, and 2) clinical care issues. As the *Logistic health service issues* theme relates to the specific context of providing oxygen (local mechanisms for obtaining oxygen, funding mechanisms, logistics of supply and follow-up) within the Australian health care system and is not directly applicable elsewhere, it is not reported here. The focus of this paper is on Theme 2, *Clinical care issues*, which has more relevance to palliative care clinicians internationally.

### Theme 2a. Clinical care issues: Assessing the patient's need for home oxygen

Specialist nurses' assessment of palliative patients' need for home oxygen is a complex process shaped by:

- i) a growing awareness that palliative oxygen is no longer the first response to breathlessness;
- ii) needing to managing the expectations of families, caregivers, and/or other clinicians; and
- iii) managing safety concerns, especially for people living alone who require oxygen.

**2a.1. Oxygen is no longer the first response to breathlessness.** There was widespread acknowledgement among participants that there were a range of pharmacological and nonpharmacological strategies that needed to be explored before home oxygen was initiated.

*I started giving people hand-held fans and, OK, try the oxygen...and they find it's a similar effect and they like it because they're in control. (Palliative Care Nurse, FG 4)*

These participants made reference to a wide range of strategies that they would encourage the patient to try before progressing to oxygen.

*I would use other tactics [before initiating oxygen] and they would be about education to the family about the benefits of oxygen, whether it's clinically indicated. (Rural Palliative Care Nurse, FG1)*

**2a.2. Managing the expectations of family members and other clinical staff.** When considering the benefits of implementing home oxygen, participants frequently had to manage expectations of family members and other clinical staff. This was more challenging if the patient had effectively used oxygen during periods of acute distress.

*The patients you send to hospital, the first thing they do [in the ambulance] is put oxygen on before they even get to hospital. (Palliative Care Nurse, FG 5)*

It was also challenging if oxygen was clinically not indicated. Despite the guidelines, it was sometimes easier to initiate home oxygen to "treat the caregiver's anxiety," which is exemplified by this quote:

*...that's the time when we would use our own concentrators...particularly in that terminal phase, where someone is distressed and the family [is] convinced 100% that the oxygen would make them feel better. (Rural Palliative Care Nurse, FG 1)*

Requests for oxygen were frequently made by families, the patient's family physician, or palliative care nurses when the patient was actively dying. In these situations, the availability of home oxygen was viewed as an essential requirement, or as a backup plan to help facilitate a home death and prevent a last minute transfer to the hospital. On these occasions, there was little alignment of clinician practice with the existing evidence and few opportunities to explore other strategies to relieve breathlessness.

*There was a time when we put oxygen out on a station [very large, isolated cattle property] and the lady...she was not entirely requiring oxygen.... It was put there to make them feel more secure in managing her at home. (Rural Palliative Care Nurse, FG1)*

**2a.3. Safety concerns.** Participants thought carefully about the safety of introducing home oxygen, assessing its effectiveness and disadvantages, and reassessing these on a regular basis. Smoking was a universal safety concern, and there were varying degrees of tolerance about its continuation in the home environment. Some participants, following team agreement, would provide oxygen even if the person continued to smoke but with caveats on its use, usually negotiated with care givers.

*Some patients are sensible when they smoke...and they'll go out and smoke and relatives will go out and smoke.. (Palliative Care Nurse, FG 4)*

Whereas, other participants were less flexible and would either not provide home oxygen or withdraw it if smoking continued to occur at home.

*We never prescribe oxygen to people who continue to smoke. (Rural Palliative Care Nurse, FG1)*

Beyond smoking, other activities where ignition was a possibility also attracted concern.

*We had a guy who went outside to the shed and use[d] an angle grinder. It all exploded in his face. He just forgot he had it on. (Rural Palliative Care Nurse, FG 1)*

The other common safety concerns were: tripping over the tubing, the potential hazard of carrying cylinders in the car, the presence of small children who might tamper with the oxygen settings, the potential harm of giving oxygen to a person who was retaining carbon dioxide, and the unreliability of the power supply in some areas.

An additional safety concern was making sure that the oxygen was provided to a person who was cognitively competent. Although several of the clinicians mentioned that safety was linked to a person's cognitive ability, there was no mention by any participants of regularly assessing cognitive status.

**2a.3.1. Patients living alone.** No participants considered being alone at home as a specific safety concern for home oxygen, but it did change the level of assessment before introducing it.

*For people who live on their own, that index of caution is just ratcheted up a little bit higher. (Palliative Care Nurse, FG8)*

Although the safety concerns participants had about a person living alone did not differ from general safety concerns, there was acknowledgement that a person living alone would need to have the physical and cognitive ability to manage an oxygen cylinder or concentrator and not get tangled up in the tubing. They were also more likely to need supportive care from neighbors or family members and assistance with activities of daily living. Additional plans were also required for people living alone, such as: a power failure emergency backup plan; access to an emergency number, a mobile phone, or an immediate alert system in place; education on the use of oxygen and its risks; ready access the oxygen in times of distress; a key outside the house; and the ability of community staff to get to the front door.

### **Theme 2b. Clinical care issues: Monitoring home oxygen**

Aspects covered in ongoing assessment include: routine assessment; when, and if, to remove home oxygen; and consideration of the burden of oxygen therapy.

**2b.1 Routine assessment and when to remove oxygen.** The schedule for reassessment of home oxygen varied across palliative care services and participants.

*If someone was severely dyspneic today and we put oxygen in, I would get them to phone me if things hadn't resolved. (Palliative Care Nurse, FG 6)*

However, a range of situations were identified that would prompt the removal of home oxygen, namely: if the person continued to smoke, the benefits did not outweigh the burdens, the acute situation for which oxygen had originally been prescribed had resolved, if the patient did not want it, if oxygen was not being used, or if the patient was actively dying and was comfortable without it.

*We often take it off patients because it's one of those things which has been put on them which doesn't need to be there and the patient is now dying. (Palliative Care Nurse, FG 5)*

However, once oxygen had been placed in the home, the security it provided often made it very difficult to remove.

*We lent it [oxygen concentrator] out and then we needed to get it back. It is very hard to withdraw an oxygen concentrator for people not approved for domiciliary oxygen because you leave them with nothing. (Rural Palliative Care Nurse, FG 1)*

Some participants tended to leave oxygen in place, even if it wasn't being used as its presence in the home acted like a safety net.

*There are many people you go [to] and they're settled and they're not anxious. They actually take the oxygen away and they say, "Oh, I'll use it when I need it"...so you just think, "Oh, it must be really a security blanket [for] when you're anxious." (Palliative Care Nurse, FG9)*

**2b.3 Consideration of the burden of oxygen therapy.** Participants recognized that the provision of oxygen in the home was not without disadvantages or burdens, especially if home oxygen meant a person may become socially isolated or if it created dependencies.

*...there are people...who [are] trapped at home because there's an oxygen concentrator there, and they forgo other things because they've found some sort of psychological security in this device, that may or not actually really be helpful.... And managing [this] continues to be a challenge...because it's about psychological dependence and anxiety. (Palliative Care Nurse, FG8)*

At times, the burden of home oxygen was considered from the carer's perspective.

*...the whole care system at home has to change, that is, "I need to give up work because what if the oxygen failed??" (Palliative Care Nurse, FG 5)*

## **Discussion**

The purpose of this study was to explore the views of experienced palliative care nurses whose responsibilities included the initiating of palliative home oxygen. The key themes highlight that there is an increasing awareness among specialist palliative care nurses, particularly in urban services, of the current prescribing guidelines and the importance of trying other therapies prior to initiating home oxygen. Of note, nurses believed that the majority of their patients' access to home oxygen fell within the current international funding guidelines. This finding is in direct contrast to a previous home oxygen study conducted over a decade ago<sup>7</sup> where higher rates of prescribing outside guidelines were reported. Greater awareness and adherence of the prescribing guidelines among palliative care nurses in the current study may reflect the emphasis placed on translation of evidence into practice and the resultant practice changes.

Beyond the stated themes, there was an underlying consideration from the palliative care nurses that the place of long-term home oxygen therapy was changing. There were explicit statements that home oxygen therapy was no longer the starting point for the treatment of breathlessness but something to be used as a last resort. Most importantly, it would seem that the time frame for this shift in terms of change of clinical practice has been relatively short. Clinician beliefs and behaviors and perceived patient and caregiver net benefits reflect the understanding from the literature.<sup>7-9</sup>

### **Strengths of the study**

This study attracted involvement by a wide range of specialist nurses with significant palliative care experience employed with a variety of metropolitan, regional, and rural practices across Australia. The study deliberately engaged more than one state and a range of geographical settings so that a range of beliefs and behaviors and service delivery models could be reflected in the findings.

### **Limitations**

The major limitations of this study include the gender and setting bias, with fewer men volunteering to participate, and the majority of participants working in metropolitan as compared with regional or rural palliative care services. In addition, these data are from nurses willing to participate. It is possible that the palliative care nurses who chose not to participate may have differing views. The large number of nurses, from several states and a variety of metropolitan services, who participated in the focus groups agreed with the confirmation of the themes.

### Implications for research

It has previously been reported that people living alone were much less likely to be prescribed home oxygen and that this could not be explained by more time in hospital, higher levels of breathlessness, or differing levels of community care.<sup>16</sup> This current study suggests that specialist palliative care nurses make little or no distinction between people with caregivers and those without, suggesting that other factors such as caregiver and family attitudes and requests for oxygen may be important considerations that need specific exploration in future work. This study has also identified some potential differences between urban and rural nurses' oxygen initiation practices that require further investigation. Exploring the impact that access to specialist palliative care medical advice and/or readily available oxygen concentrators have on home oxygen usage are important lines of inquiry. Better understanding of the role of prophylactic oxygen prescribing for people in more isolated communities is also required.

It seems that practice has changed for palliative care nurses and that having permission *not* to prescribe or initiate oxygen seems to be having an effect on practice.<sup>10–12</sup> This change needs to be more formally assessed, especially across care settings. It will also be important to repeat this study in another 5 years as the impact of the changing evidence base finds its way into guidelines and funding policies.

The relative weightings of each of the issues raised by specialist palliative care nurses need to be the focus of future research. By understanding the magnitude of each issue, work can be developed to further optimize the use of home oxygen.

In parallel with these focus groups, the views of respiratory nurse specialists/consultants/practitioners and medical specialists were sought. This will be reported separately, but needs to be extended into other disciplines that seek home oxygen prescriptions.

Most importantly, the current findings suggest that there is a need to find out from current and former caregivers how they view oxygen when caring for someone with refractory breathlessness. It would seem, from the findings of this paper, that caregivers may hold a key to explaining much of the oxygen that is prescribed outside guidelines.

### Implications for practice and policy

These results support a continued pragmatic approach to the use of oxygen, with the recognition that there are factors beyond reduced oxygenation that influence prescribing. The concept of an n-of-1 trial with set review for net benefit (burden and symptom relief) has been suggested, and operationalizing this in routine practice may further refine the use of the therapy.<sup>12,24,25</sup> The results also raise the issue of who should actually be routinely assessing and monitoring the need for home palliative oxygen and whether a similar system for nonpalliative oxygen prescribing is required.

### Conclusion

Oxygen is a common intervention in the palliative home setting. In this study, palliative care nurses involved in initiating or prescribing oxygen often reported using oxygen as a second-line treatment after other interventions had been trialed and had not provided sufficient symptomatic benefit. Safety issues were a universal concern; however, a person

living alone did not emerge as a specific concern among the nurses interviewed.

### Author Disclosure Statement

No competing financial interests exist.

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