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Caregivers' perspectives on the use of long term oxygen therapy for the treatment of refractory breathlessness: a qualitative study

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Abstract

Context

Despite limited clinical evidence, long term oxygen therapy (LTOT) is used for the management of refractory breathlessness in people with life-limiting illnesses who are not necessarily hypoxaemic.

Objectives

The aim of this study was to understand caregiver factors associated with caring for someone with LTOT from the perspectives and experiences of caregivers themselves.

Methods

The qualitative study used semi-structured interviews. The study was conducted in two states in Australia. Participants (n=20) were self-nominated caregivers of people receiving LTOT for refractory breathlessness in the palliative setting.

Results

Data analyses established one overarching theme titled: '*Oxygen giveth (something to help caregivers relieve breathlessness) and oxygen taketh away (from patients who lose some autonomy)*'. The theme captured caregivers' feelings of extreme distress in response to witnessing refractory breathlessness, and oxygen fulfilling several critical and beneficial roles in this context. In parallel caregivers also explicitly and implicitly articulated several downsides to the use of LTOT.

Conclusion

Caregivers find caring for someone with refractory breathlessness extremely distressing. The benefits of LTOT are often over-estimated while its potential harms are under-estimated. As significant stakeholders in care of people receiving LTOT caregivers should be provided with opportunities to collaborate with clinicians in evidence based decision making and efforts should be made to provide them with information and education about the most effective pharmacological and non-pharmacological strategies to manage refractory breathlessness in a palliative care setting including the appropriate use of LTOT to enable them to do so.

Introduction and background

Breathlessness is a common symptom for people with life limiting illnesses with prevalence and intensity often increasing closer to death [1, 2]. The most effective way to relieve breathlessness is to maximally treat the underlying cause [3]. Chronic breathlessness after optimal treatment of the underlying cause(s) is termed 'refractory', which may still be ameliorated to some degree by pharmacological and non-pharmacological means [3, 4].

While refractory breathlessness remains to a large degree, undertreated, the evidence base for its treatment is increasing [5, 6]. Indeed it is now argued that relief from chronic refractory breathlessness, like pain, is a basic human right and should be seen by clinicians as a priority [7]. Oxygen has, to a large extent, been the panacea treatment for people with various chronic lung, cardiac and neuromuscular conditions regardless of whether or not they were hypoxaemic. It is an important part of the clinical toolkit as an approach for the care of people with hypoxaemia or those who have breathlessness at rest or on minimal exertion [8]. Yet evidence from a randomised control trial has shown that palliative oxygen therapy is no better than medical air [9].

The prescription of oxygen may also be driven by factors other than research evidence or clinical benefit. Furthermore, the prescription of domiciliary oxygen may compromise patients' autonomy and mobility [10]. For example, an earlier study showed that people with caregivers were more likely to receive home oxygen; and people who lived alone had twice as many visits by a clinician before oxygen was prescribed than those who did not. Furthermore, not having a caregiver significantly reduced the likelihood of home oxygen [11].

The subsequent qualitative study exploring socio-cultural and clinician factors shaping oxygen prescribing, identified that clinicians often provided oxygen for its 'psychological benefit of the caregiver rather than the physiological benefit of the patient' (p. 5) [12]. Clinicians indicated that they often felt under pressure from families to prescribe oxygen in the home to treat what they regarded as caregiver anxiety [12]. As clinicians did not appear to discriminate between those who lived alone and those who did not on the basis of safety factors or other ongoing concerns we were keen to explore the use of home oxygen from caregivers' perspectives. To

the best of our knowledge, only one quantitative study has been undertaken thus far specifically exploring caregiver burden in the setting of LTOT. This study found that caregivers quality of life was severely affected when caring for a person with COPD and on LTOT [13]. Thus, the aim of the current qualitative study is to further understand caregiver factors related to caring for someone with refractory breathlessness, LTOT and a life-limiting illness from the perspectives and experiences of caregivers.

Methods

Theoretical approach

Applying a constructivist grounded theory approach allowed us to view the data as emerging from an interactive process contingent upon the social context [14]. Thus, interviews were regarded as the co-construction of meaning resulting from the inter-relationship between interviewers and participants reflexively taking account of the interviewers' backgrounds as experienced specialist palliative care nurses.

Study setting and participants

The study was conducted at two metropolitan specialist palliative care services in Australia: Sydney, New South Wales; and Adelaide, South Australia. Both services provide a regional program of care encompassing inpatient, consultative outpatient and community care. Participants were self-nominated direct caregivers of people receiving LTOT for refractory breathlessness and a life-limiting illness irrespective of whether or not they were hypoxaemic. Participants were also required to be over 18 years of age and able to converse in English and were not receiving direct care from the research team. The research team recruited participants through the specialist palliative care clinical trials teams and ambulatory palliative care and respiratory services at the participating sites.

Written information about the research project and inclusion criteria were disseminated through these networks. The researchers at each site were either contacted directly by interested participants or, following consent, were provided the names of potential participants by clinicians and contacted by the researcher. Participants were informed that they could withdraw from the study at any time without compromise to the care of the patient through whom their engagement was generated.

Ethical approval

Ethical approval was obtained from the Southern Adelaide Clinical Human Research Ethics Committee (HREC) reference number 490.13 and St Vincent's Hospital Sydney HREC reference number LNR/14/SVH/57.

Semi-structured interviews

An experienced qualitative researcher and palliative care nurse (AC) oversaw data collection, while a research assistant (CL) and the specialist palliative care clinical trials nurses at each study site, trained in interviewing skills, conducted face-to-face interviews. Interviews were conducted between July 2014 and June 2015. Participants provided written or audio-recorded consent and determined where the interview took place. An interview topic guide comprising six open-ended questions was used (Appendix 1) as a prompt. Participants were asked to share their experiences of caring for someone with refractory breathlessness, a life-limiting illness and their perspectives and expectations of LTOT. Interviews lasted between 5 and 30 minutes and were audiotaped and later transcribed verbatim. In keeping with a constructivist grounded theory approach data collection and analysis occurred simultaneously and the interviewers kept field notes to document additional insights or observations to aid this process as well and to facilitate research reflexivity during the research process. Recruitment continued until researchers agreed that the generation of new properties from coded categories with data were saturated.

Data analysis

Data were organized using the software program NVivo 9 2010 and were analyzed employing constant comparison first of data with data, then comparisons between codes and subsequent data. AC, an experienced qualitative researcher and palliative care nurse developed the initial coding frame at the outset of data collection and iteratively developed categories and memoing through the lens of identifying particular features, tensions and inconsistencies about perspectives and experiences of LTOT including deviant cases. When recruitment reached twenty participants KB, and JP, also academics with a nursing background in palliative care, independently reviewed transcripts and contributed to the refinement and elaboration of categories. At this stage AC, KB and JP agreed that categories were saturated and recruitment was discontinued. MA and DC further interrogated coding categories and findings

providing a specialist medical perspective. All authors continued to discuss coding categories and themes until consensus was reached on final themes.

Findings

A total of 20 caregivers (male n=7; female n= 13) participated in the study (Sydney n=6 and Adelaide n=14). Caregivers' relationships to recipients of LTOT included: spouses (n=14), friends (n=1) and/or adult children (n=5).

Data analysis yielded an overarching theme we have named: '*Oxygen giveth and oxygen taketh away*'. That is, for the most part, caregivers articulated oxygen as having a vital and unquestionable life sustaining role for the people they cared for, and was perceived to be central to managing what they regarded as extremely distressing symptoms. From the caregivers' perspectives, while oxygen added a clear benefit to their loved one's life including quality of life, there was also a downside to long-term oxygen use. The overarching theme of perceived benefits and costs included the following sub-themes:

- Oxygen giveth: *Oxygen as 'breath of life'; Oxygen 'all things to all people'; Oxygen prescribers;*
- Oxygen taketh away: *The oxygen spiral; Oxygen-costs and burdens*

Oxygen giveth

Oxygen as 'breath of life'

Caregivers without exception prefaced the necessity of using oxygen in the context of what it was like caring for someone with refractory breathlessness. They described emotionally what it was like to be powerless 'watching on' when a person is suffering with extreme breathlessness as the following participant, a patient's wife, expresses:

“I just find it a bit distressing to watch but I can't do anything about. Yeah.” P14

Watching a person struggle for breath, someone they knew and loved, was intensely distressing for caregivers. We term the way in which caregivers described these feelings as 'primal distress'. A patient's daughter conveys this distress in the following quote:

“You know, because honestly when you see someone’s lips going blue and they are trying to breathe and can't, you know, it is horrible. You know, especially if it is your dad or your mum or somebody you love. It is horrendous. It is horrendous. So at least with the oxygen you quickly stick it up his nose and it helps a bit. It takes a while to kind of get in them or something but yeah.” P13

In the context of this ‘primal distress’, caregivers frequently spoke about oxygen as a life-saving measure as the next quote demonstrates:

“The advantages are it is keeping my husband alive. He can't live without it, we know that.” P10

Caregivers like the wife caring for her husband in the quote above often spoke of oxygen as a lifeline without which the person they were caring for would be dead.

Oxygen: ‘all things to all people’

Caregivers articulated the role of oxygen as having a variety and number of advantages from their perspectives. For instance, along with its vital function of keeping people alive, caregivers articulated oxygen as something that had a diverse and varied range of helpful functions.

“Well, I mean, I would say that if it helps them breathe and it helps the heart pump the water out a bit, it honestly keeps them a bit more alive I guess. And apart from my father, I know the benefits it has worldwide for all sorts of things.” P13

The daughter of a patient quoted above considers oxygen to have a central therapeutic role not only in congestive cardiac failure management but also for a diverse range of conditions. In other words, oxygen is regarded as universally ‘good’ and life sustaining.

Through the lens of this ‘global’ perspective, oxygen could be regarded as having an important role in helping both the carer themselves, as well as the person they cared for to feel safe as the next quote by a patient’s wife demonstrates:

“Both physical and probably emotional. It’s, I think for him, it is a feeling of safety: “I can breathe.” P3

Caregivers frequently spoke in terms of what they considered the emotional as well as physical benefits of oxygen. For some caregivers the relief of anxiety and the emotional benefits of oxygen were significant. The patient's daughter in the next quote contrasts what she refers to as the 'actual' or real effects of oxygen with her observed effects:

“I think, from an outside perspective. I don't know how much it actually benefits her but she is much more relaxed. Much more relaxed.” P1

This 'global' perspective was articulated by several caregivers in terms of the use of oxygen for purposes other than healthcare as the next quote, from the same caregiver demonstrates:

Interviewee: “No, I want some (oxygen)! I asked if I could (have oxygen) and the guy said to me, well you will need a lot. Because I know it is really good for your skin. And I am like, “I would like some of that.” Because it is, some people go and sit in oxygen things for like an hour at lunchtime.” P1

Oxygen prescribers

The initiation of oxygen prescriptions were from a variety of reported sources including, hospital discharge nurses, GPs, palliative care nurses and medical staff. Sometimes however, caregivers initiated oxygen themselves as the next quote by a patient's wife shows:

“And he was going to be discharged so I rang the nurse on the floor and I said there is talk of John being discharged. Oh yes, yes. Yes. I said, well, sorry but you have got him longer because I can't get oxygen without a doctor's prescription and until there is oxygen he can't come home.” P3

The quote above shows how caregivers can position themselves as having a significant influence on prescribing of LTOT and, in this case, whether a patient may or may not be discharged.

Although oxygen was to a large extent, regarded as providing a necessary life-line that had little in the way of disadvantages, data analysis also highlighted evidence of reported negative effects of oxygen in caregivers' talk.

Oxygen taketh away

Some caregivers did not express the vital role of home oxygen independently from what they regarded as its other less positive effects, as encapsulated in the following sub-themes.

The oxygen spiral – ever downwards

Caregivers' talk contained the frequency and duration of oxygen use, with a common theme being that the patients' oxygen use escalated overtime as this quote by a patient's wife shows:

“And he does certainly rely on it. He has the oxygen more and more now, during the day. It was when he first got it (oxygen), it was just at night, just to sort of ease his night time breathing. But he is having it pretty much all the time now.” P12

It was not unusual for caregivers to articulate what appeared to be an increasing frequency of oxygen use over time as the quote above shows.

Oxygen-costs and burdens

When asked directly about the possible disadvantages of home oxygen, caregivers responded, for the most part, in terms of the equipment required, and difficulty navigating around and beyond the home environment because of the equipment required to deliver home oxygen; financial costs, and noise of the oxygen concentrator:

“Of course, you are limited by, I call it *'the slime'*. Because everywhere we go there is a trail of plastic behind. So that is a limitation in itself. But it does, you know, it can go from anywhere in the unit, it can go without disconnecting from the oxygen. It means whatever he is going to do he can do a little bit easier.” P9

By naming the oxygen tubing in this way, a patient's husband implies how their home is transformed as a result of having a trail of green oxygen tubing in their home. The oxygen tubing whilst providing independence is also conditional, and a reminder that

both the person cared for and their caregiver can venture only as far as the oxygen line without further support and meticulous planning.

Costs and burdens became most significant when caring for someone requiring home oxygen had significant impact on caring as well as presenting significant concerns for caregivers as the caregiver in the next quotes describes:

“When she is on it (oxygen), yeah. I wake up in the night, every hour and a half, to check her. She just knocks it off, it is off, and I don’t know how long it has been off and I put it on and she is half asleep and she will try and put it on and she thinks she has put it on and she will fall asleep again. And I don’t know if it is because of lack of oxygen she is not waking up or just tiredness. I put it on, go back to bed. Another hour I will come and it is off again. I said, what can keep it on I don’t know? So I don’t sleep too good because I am frightened it is going to come off and I don’t know the ramifications if it stays off for more than 4 hours, what will happen to her?” P17

The quote by a patient’s husband above shows how oxygen is deemed necessary for his wife thus contributing to his anxiety about what might happen should it come off and resulting in sleepless nights for both parties.

Furthermore, having home oxygen prevented people from engaging in usual social activities or created barriers to meeting a person’s wishes at end-of-life as this quote by a daughter of a patient shows:

“I have wanted her, to take her up to Queensland to do something that she had wanted to do but I rang the airlines about the business of travelling with the oxygen and look, while we could get, we could take our oxygen on the plane or get their oxygen, it was just going to be a bit complicated. I mean I wasn’t going to take the oxygen concentrator with us for when we were there and we were going to be there for a couple of days and I just sort of thought, oh look it is just the oxygen making it a little bit more complicated. In the end I just decided it was too hard.” P2

In some instances therefore, the presence of oxygen prevented the ease with which the person could move from one space to another and the caregiver saw the lack of ease of mobility as a lost opportunity to fulfil a person's wishes at the end of life.

Discussion

Evidence-based guidelines for the management of refractory breathlessness advocate treatment of reversible causes, consideration of non-pharmacological treatments, and titrating regular oral sustained release morphine [15]. Evidence from randomized control trials has shown that the value of oxygen for refractory breathlessness is limited [3, 16]. Yet our study has shown that, to a large extent, caregivers consider oxygen to have a significant role in the relief of refractory breathlessness. These findings are supported by those by Goldbart et al who found that caregivers equated LTOT as important for patients' quality of life [17]. Our findings go much further however, highlighting how LTOT, to a large extent was regarded by caregivers as critical in keeping the person they are caring for alive. Our analysis of data has shown that, for caregivers, oxygen plays a central role in helping them retain some degree of control in situations of significant primal distress and powerlessness as they watch on helplessly.

On one hand, caregivers regarded oxygen as a drug, constructing it as the 'magic pill' of refractory breathlessness thus over-estimating its potential therapeutic benefits. On the other, the significance of oxygen as a drug in terms of its side effects was, for the most part, under-estimated. This conception of oxygen has several important implications highlighted by our study. Caregivers play a central role in advocating LTOT and its management and administration in the home. Unknowingly however, they may be inadvertently contributing to patients' reliance on oxygen. Consistent with findings from a Brazilian study exploring the quality of life and burden in carers for people with COPD [13], our findings also show that just as oxygen can 'bind' patients it can also 'bind' caregivers contributing to possible caregiver fatigue and potentially other burdens including those of a social and financial nature. Just as people who have been prescribed oxygen often have to balance their now restricted life world and increasing dependency, with the advantages that oxygen provided [18] so do caregivers.

Oxygen equipment and its associated noise can become a symbolic reminder that the person is permanently tethered to the machine and therefore to their home. It has the potential to alter the meaning of home [18, 19] and for some caregivers, may serve as a constant reminder of a person's underlying chronic illness, physical limitations and approaching death [19]. Our findings also highlight the widely held view that oxygen is life sustaining; perhaps revealing a gap in understanding of the refractory nature of breathlessness and poor prognosis. Alternatively, it may be that caregivers hold these perspectives simultaneously, understanding both realities of living and dying or what MacArtney et al have coined as a 'parallax experience' [20].

While non-pharmacological approaches are a key component of the management of refractory breathlessness [3] and can help improve patients' mastery over their breathlessness [4] the caregivers we spoke with did not articulate these approaches to management. Care models, to a large extent tend to focus on patients. Our findings support the call by Maddocks et al that non-pharmacological and pharmacological interventions aimed at improving the symptoms of refractory breathlessness for patients should include caregivers [21]. In addition, already existing programs aimed at equipping caregivers to care for someone with a life-limiting illness should include coping with and managing refractory breathlessness. Caregivers' time is precious and such programs and/or interventions need to be evaluated appropriately to ensure they meet caregivers' needs as well as patients and make a difference to the quality of life of both.

Clinicians themselves may not be fully aware of the evidence-based management of refractory breathlessness including the potential role of LTOT for some people with life-limiting illness. Furthermore the need for appropriate and formalised prescribing and administering of oxygen as a drug that is rationally and precisely prescribed often goes unrecognised in the practice setting [22]. In other words, clinicians like caregivers tend to over-estimate the benefit and under-estimate the potential harms of oxygen therapy. Even when aware of the evidence, clinicians find it difficult to balance their own knowledge and views with the expressed needs of patients and caregivers in practice situations [12]. This conflict often poses an ongoing and difficult dilemma for clinicians attempting to provide optimal care [23] and they too may find it difficult to watch on 'helplessly'.

Strengths and Limitations

A key strength of this study is that it included caregivers from two states in Australia. The study had several limitations; caregivers who self-nominated may have been those with a particular or stronger views about LTOT. For example, caregivers who elected to participate may be those caregivers most likely to advocate for LTOT. In addition the study excluded participants who could not speak English. Furthermore, participants were drawn from metropolitan services and the research warrants extension to rural and remote settings. In addition, principle researchers come from a clinical background in specialist palliative care and interpretation of data through this lens may have limitations. For example, all researchers were fully aware of the clinical evidence for LTOT and this may have influenced the questions asked, as well as data analysis. Further, our previous held views concerning the use of LTOT and the role of carers may have, to some degree influenced how we positioned them and their role in managing LTOT.

Implications for practice

Oxygen prescribing for people with refractory breathlessness and a life-limiting illness has clinical, social and economic limitations. For caregivers, LTOT provides a tangible material device to respond to the significant physical and emotional distress resulting from caring for someone with refractory breathlessness at home when ‘watching on’ and ‘doing nothing’ is simply not an option. Oxygen equates with the very maintenance of life itself and in this sense may be seen as a historical and cultural panacea not only for informal caregivers but also for clinicians. This means caregivers can become significant stakeholders in the prescribing and administration of LTOT situating them as unpaid health workers. Moreover, there is clearly a disconnect between the scientific regard for palliation of refractory breathlessness and how caregivers, and perhaps to a large extent clinicians regard it. The question then becomes one of how these disparate concerns might be reconciled. This is a thorny question and one that extends to much wider debates concerning evidence based practice and the positioning of patients and families in healthcare and research. Nevertheless our findings translate into several recommendations. In making these recommendations, however, we are aware that there is more to this question than we have been able to fully address. First, the prescribing and management of LTOT is often governed at an institutional level while caregivers are usually supported through primary health care services potentially resulting in poor continuity of care. Second,

providing caregivers and frontline clinicians with information and education about the appropriate use of oxygen for refractory breathlessness in a format that meets their needs might contribute to evidence-based practice. Most critical however, is finding strategies to best support caregivers who bear witness to this most distressing symptom [24]. Complex interventions such as those delivered in breathlessness clinics need to address the individual and specific needs of caregivers as well as those of patients and need to be delivered in a flexible manner [21]. Finally researchers need to account for the critical role of caregivers as well as patients when designing studies concerning palliation of refractory breathlessness.

Disclosure

The authors declare that we have no competing interests.

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