



**SOUTH EASTERN SYDNEY
ILLAWARRA
NSW HEALTH**

**The Rural Research Capacity Building Program 2008
Final report for research project:**

“Oxygen ...you can’t live without it.”

**Perceptions of rural people using domiciliary
oxygen**

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Glossary of Terms

AHS	Area Health Service
ALF	Australian Lung Foundation
ARIA	Accessibility Remoteness Index of Australia
Clinician	A professionally qualified, registered healthcare worker with direct patient contact
COPD	Chronic Obstructive Pulmonary Disease
Cor Pulmonale	Cor pulmonale is an alteration in the structure and function of the right ventricle caused by a disorder of the respiratory system
CPAP	Continuous positive airway pressure
Domiciliary	For use within the home
Dyspnoea	Breathlessness
Hypoxia	Inadequate oxygen at tissue level
Hypoxaemia	A deficiency in the concentration of oxygen in arterial blood
IRCST	Institute of Rural Clinical Services and Teaching
LTOT	Long term oxygen therapy
NIV	Non – invasive ventilation
Nocturnal	Occurring during the night
RHD	Rural Health Directorate
RRCBP	Rural Research Capacity Building Program
SESAHS	South Eastern Sydney Illawarra Health Service
TSANZ	Thoracic Society of Australia and New Zealand

Abstract

“Oxygen ...you can't live without it.”

Perceptions of rural people using domiciliary oxygen

Background: Oxygen is prescribed for patients with respiratory illness to ensure adequate oxygenation to tissues and vital organs. Previous studies with urban patients addressing the 'lived' experience of domiciliary oxygen have shown they experienced social and physical isolation.

Aims: This qualitative study described rural patients' perception of how oxygen therapy has impacted upon their life.

Method: Data were obtained from semi structured interviews (n = 5) which were transcribed and coded to identify themes using phenomenological processes.

Results: Three broad themes were identified.

- *Oxygen as an enabling paradox.* Participants acknowledged that concentrated oxygen enabled them to do more, but was inconvenient. Those who had access to portable oxygen reported less restriction.
- *Oxygen as an inevitable necessity.* Participants acknowledged that oxygen was an inevitable part of their disease process.
- *Life modifications to accommodate the theft of independence.* Participants articulated grief for the loss of their former self and strategies employed to accommodate their decline in health.

Conclusions: Social and geographical isolation identified in previous studies were not replicated in this rural study. Access to oxygen enabled participants to live, but access to affordable portable oxygen enabled the freedom of community participation within the individuals' health limitations.

Key words:

Chronic lung disease, domiciliary, oxygen, perception, rural health

Executive Summary

Background:

Chronic respiratory disease (e.g. Chronic Obstructive Pulmonary Disease) is an insidious, progressive disease affecting adults. Those with an advanced disease state resulting in respiratory failure require oxygen. Once oxygen is prescribed it is rarely withdrawn becomes part of ongoing treatment. It is those patients using oxygen in this manner that we hope to better understand the lived experience via this study. Previous studies have demonstrated people with domiciliary oxygen experience social and physical isolation.

Aim:

This study aims to understand the lived experience and the meanings rural people attribute to those experiences when using domiciliary oxygen as part of the medical management of their lung disease.

The literature review demonstrates perceptions of oxygen dependant people, but is metro/urban centric in its approach; no data is yet available from the rural perspective.

The principle investigator has an ongoing interest in the lived experience of people with chronic disease. Anecdotal reports of experiences from people using oxygen and limited studies provided the principle investigator with the impetus to seek further understanding.

Methodology:

This qualitative study was guided by phenomenological principles and used semi structured interviews to explore five rural participant's perceptions of domiciliary oxygen as part of their treatment.

Transcripts were analysed for emergent themes to enable the open coding process. This was followed by axial coding by organising the data to make connections between the main categories and subcategories. The main categories became the major themes of the study, comprised of the grouped subcategories.

Findings:

Three broad themes were identified after an analysis of the transcripts. Each theme comprised a set of sub themes.

The first theme, '*Oxygen as an enabling paradox*', explored the subthemes of

- Feeling safe, having more energy, confidence and independence
- Oxygen as life giving
- Oxygen improves sleep
- Frustrations of being tied to a tube
- Fear when oxygen is not available, which can lead to a panic, breathlessness cycle
- Financial cost of oxygen

Under the second theme, '*Oxygen as an inevitable necessity*', there were subthemes that considered

- Relief at provision of oxygen but expecting it to do more than it did

- Oxygen as an inevitable part of their disease
- Oxygen as a part of life, part of the family, like a baby
- Humidity and heat affecting shortness of breath and oxygen use
- Nasal mucosa drying up because of the oxygen
- Oxygen tubing being annoying and being tangled up in it
- Oxygen as an extension of the person
- Humanisation of the oxygen concentrator

The third theme, *'Resignation and modification to accommodate changes in independence'*, discussed the subthemes of

- Access to portable oxygen increases independence
- Without access to portable oxygen, people use other strategies
- Use of social networks, family and friends to remain socially connected
- Battling shortness of breath, but not brooding on it, getting on with life
- Compromises the individual makes to accommodate shortness of breath
- The feeling of grief at the loss of their former independent self

Conclusions and recommendations:

Findings of the study consistently demonstrated that despite poor health and oxygen dependence participants did not report social isolation as was reported in previous studies. Participants felt that oxygen had increased their independence and that access to portable oxygen enabled the freedom to choose different activities away from the home with less inconvenience.

Resilience and social capital of the participants enabled strategy development to assist with dyspnoea, panic, access to portable oxygen and activities of daily living. However, all participants confirmed the findings of previous studies in relation to grief/loss of their former self and whilst oxygen dependent, attributed their situation to their lung condition not the oxygen therapy.

This study raises awareness of living with respiratory failure and oxygen therapy. For the patient, panic, dyspnoea and oxygen availability are all real fears. The availability of portable oxygen makes the ability to socialise within the patients' physical means more attainable; however this luxury is currently limited to those with financial means. Considering that chronic lung disease is a disease of smoking, which is associated with those from a lower socio-economic group, access to portable oxygen for most is unattainable. Policy makers should consider the provision of portable oxygen to oxygen dependant people not as an ancillary service but as intrinsic to the care for this socio-economically disadvantaged group. Means testing doesn't currently apply to life saving devices such as pace-makers; income testing on oxygen should be reviewed to ensure device equity.

This study has demonstrated perceptions of people using oxygen from an inner regional area in Australia. Further studies using a similar methodology would be encouraged for outer regional, remote and very remote Australia, to determine the correlation between resilience and social capital in these communities with people using domiciliary oxygen.

Introduction

This report is the culmination of a two year research grant funded by the NSW Institute of Rural Clinical Services and Teaching. It is intended that this report will inform current practice in relation to the provision of oxygen for people with chronic lung disease.

The report explains why there was a need to undertake the research, and how it was undertaken. The report concludes with recommendations and future research opportunities to augment this current research.

The purpose of the research was to determine if a difference existed between the urban and rural experience of living with domiciliary oxygen as part chronic lung condition treatment.

Background and literature review

Chronic respiratory and cardiac diseases are responsible for over 25% of the total burden of disease and injury in Australia⁽¹⁾. The economic impact of Chronic Obstructive Pulmonary Disease (COPD) alone has been assessed at \$8.8 billion⁽²⁾. Of this total cost, \$6.8 billion was attributable to lost productivity, \$0.9 billion was direct health expenditure, \$0.9 billion from welfare payments and lost taxation revenue and \$0.3 billion was in indirect costs such as aids, home modifications and funeral costs⁽²⁾.

The socio-economic gradient in chronic lung disease is greater than any other disease⁽³⁾, with a lower socio-economic status being a predictor of lung function in smokers and non-smokers⁽⁴⁾. Smoking is the single biggest contributing factor in chronic lung disease, with air flow obstruction more prevalent among smokers than non smokers⁽⁵⁾.

With regard to respiratory disease and rurality, northern hemisphere countries report lower incidence of asthma, by comparison to Australia, where asthma hospitalisation rates are variable by region, but asthma related deaths are increased with remoteness⁽⁶⁾.

Despite improvements in the management of chronic lung disease, the burden of chronic respiratory disease on the healthcare system is increasing^(7, 8). The prevalence for COPD, (responsible for the largest burden of all respiratory diseases at approximately 40%), is projected to double from 2008 – 2050⁽²⁾. These increases in respiratory disease are thought to be related to the projected increase in the age of the population⁽⁹⁻¹¹⁾. As a result long term treatment with oxygen in the patients' home will become more prevalent.

At present there is considered insufficient coordination and inequitable access to best practice patient care in chronic disease⁽¹²⁾. In rural regions access to services is further challenged due to geographical locations, linkages with specialist services and diagnostic access⁽¹³⁾. For patients with respiratory disease, gaps have been identified in spirometry, non invasive ventilation (NIV), home NIV support, long term oxygen therapy (LTOT), pulmonary rehabilitation, smoking cessation and education for chronic disease self management interventions⁽¹⁴⁻¹⁶⁾. People with chronic conditions represent a burden to health care resources and attention is often focused to acute

disease treatment as opposed to cost effective home management and exacerbation prevention ^(12, 17).

The primary symptom of chronic respiratory disease is breathlessness which is described as a “subjective experience of breathing that consists of qualitatively distinct sensations that vary in intensity” ⁽¹²⁾. It is a disabling symptom that is frightening for the patient and distressing for carers to witness ⁽¹⁸⁻²⁰⁾. In studies considering COPD and the experience of breathlessness, the main themes that emerged were in relation to fear, panic and anxiety associated with exacerbation of symptoms and worsening dyspnoea ^(12, 18, 19, 21). The “invisibility” of breathlessness ⁽¹²⁾ has been described as a disability that is not visible at rest, resulting in limited response from health services. The stigma surrounding breathlessness adds an additional dimension of suffering to the illness experience.

Anxiety and depression is reported as being prevalent in patients with chronic respiratory diseases, as are feelings of hopelessness, worthlessness and low self esteem ⁽²¹⁾. Inadequate supply of oxygen to the limbic system and other parts of the brain that mediate emotional behaviour may contribute to emotional effects and life quality in people with chronic respiratory disease ⁽²²⁾.

Room air provides 21% oxygen. If a patient requires a higher concentration than this, usually due to a disease process or other trauma, supplemental oxygen is provided. Oxygen therapy is used to correct hypoxaemia and prevent hypoxia ⁽²³⁾. An oxygen concentrator can deliver oxygen concentrations of 24 – 40%.

Patients with chronic respiratory failure benefit from oxygen and the results of placebo controlled trials of long term oxygen therapy (LTOT) have shown that it improves survival, reduces polycythaemia, slows the progression of pulmonary hypertension and cor pulmonale and improves quality of life ⁽²⁴⁻²⁶⁾. There is no evidence that patients who continue to smoke or have symptomatic dyspnoea secondary to de-conditioning will benefit from oxygen therapy ⁽²⁷⁾. LTOT is administered via an oxygen concentrator, which have been commercially available since 1984 ⁽²⁸⁾. The concentrator is a stationary unit powered by electricity that draws air into the unit, where it passes through a molecular sieve that absorbs nitrogen to leave a high concentration of oxygen that is delivered to the patient ⁽²⁹⁾. To be eligible to receive domiciliary oxygen the patient is required to undergo arterial blood sampling and arterial oxygen levels need to be at 55mmHg or less ^(15, 26, 30). Oxygen is an expensive therapy and concentrated oxygen is the more efficient modality, with portable oxygen reserved for periods of time away from the home. Access to portable oxygen enables the patient to attend outpatient and general practitioner appointments and well as maintaining social contact outside of the home with family and friends ⁽²⁸⁾. Oxygen provision is currently means tested.

Search Strategy:

A literature review was undertaken using Clinical Information Access Project (CIAP) and databases searched were the Cochrane Collaboration, Medline, Pubmed, Cinahl and Embase. Search terms included oxygen, rural, dyspnoea, perceptions, chronic obstructive pulmonary disease, chronic lung disease, domiciliary and community. Dates chosen were from 1996 to the present.

Whilst there was extensive material about COPD, disease prevalence, disease burden and oxygen benefits, little has been written on the experience of the person receiving oxygen. Due to limited results a snowballing technique was used to obtain references from the reference lists of the limited material available.

The principle investigator sought assistance from a health librarian, and again it was found that limited material was available about the lived experience with oxygen.

A repeat search was undertaken prior to reporting to determine if new material was available since the original literature review and only an unpublished American thesis abstract was found, but the author was unable to be contacted.

There were three studies found relating to perceptions and the lived experience of oxygen. A study by Ring and Danielson ⁽³¹⁾ in 1997 was undertaken in Sweden to describe the patient's experience with the use of long term oxygen and managing their chronic disease. The study was undertaken in a county in the north of Sweden with approximately 135,000 inhabitants spread over a 100km radius. All participants were interviewed in their own homes. Four main themes were identified in the study. They were: "*restricted to time and room, an advantage for the body, living in one's own life rhythm*" and "*put up in order to live*" (Ring and Danielson, p 340).

In the restricted to time and room theme it was noted that participants' on LTOT are mobility restricted and they may not be free to go where they choose due to electricity availability and concentrator weight. The individual needs to plan trips away from the home in advance and make contingency strategies for oxygen provision and rest stops. Under this theme participants' also reported that weather with low temperatures or air pressure can be more restrictive. Under the theme *an advantage for the body* the authors found that participants' had an awareness of their body's need for oxygen and this awareness helped with the acceptance of the treatment, however dependence upon the treatment was perceived as difficult. The *living in one's own life rhythm* theme considered how the participants' know their own body and how to manage situations and do things at their own pace. *Put up in order to live* was the description used to explain how participants' modify their life with long term oxygen and they put up with the oxygen in order to make it possible to live.

The authors' surmise from their study that individuals use adaptive strategies to deal with their chronic sickness and the transition between phases of disease decline are gradual with no clear divisions. They also conclude that patients with LTOT tend to be socially isolated and their social networks were

limited. The authors also noted that spouses must also deal with the loss of social activities.

In an unpublished work by Crockett, Wilson, Antic and Greville ⁽³²⁾, the authors concluded that patients' experienced social isolation, embarrassment and grief and loss for their former selves when using LTOT. Semi-structured interviews were undertaken in Adelaide, South Australia and de-identified data transcribed for coding and thematic analysis. Categories and themes were developed around the objectives of the study. The 12 predetermined themes were identified, against which the interviews were based. They were: stigma shame, embarrassment, social isolation, dependence, physical limitation, self consciousness, difficulty with usual tasks, adaptation, integration, defeat, and compliance and adherence which equated to acceptance.

In a Japanese study undertaken by Tada, Hashimoto, Matsushita, Terishima, Tanioki and Nagamine ⁽³³⁾, the authors attempted to clarify the roles of self management, life satisfaction and quality of life (QOL) of patients receiving home oxygen therapy. Life satisfaction was defined as something that spiritually supports the patients and QOL was defined as the living environment which included activities, state of health and quality of living, physical symptoms and economic state. The authors concluded that family role function and social activities were shown to be closely related to life satisfaction and having a stable economic state. A clear role in the family unit and self respect where clear characteristics of individuals with high levels of life satisfaction.

The literature review demonstrates perceptions of oxygen dependant people, but is metro/urban centric in its approach; no data is yet available from the rural perspective. Since the publication of previous research on the topic, advances in technology has enabled the manufacture of portable oxygen concentrators as a means of providing people with portable oxygen.

The literature review indicates the need for further research of people using domiciliary oxygen across rural and remote regions. In light of recent developments in portable oxygen, there is a need for further exploration regarding this area across all geographic regions.

Aims of the Research

This study aims to understand the lived experience and the meanings rural people attribute to those experiences when using domiciliary oxygen as part of the medical management of their lung disease.

Method

A qualitative study was planned where participants participated in a semi structured interviews exploring the person's perceptions of oxygen as part of their treatment. The semi structured interview was chosen over the informal conversational interview as it had the advantage that data are more systematic and comprehensive ⁽³⁴⁾.

Ethics approval for this research was received from The Human Research Ethics Committee of The University of Wollongong and South Eastern Sydney Illawarra Area Health Service (SESAHS) on 25th May 2009 (reference: HE09/085).

The study sample was limited to patients who reside within the geographic region of the Rural Health Directorate (RHD) of SESAHS, which covers from Gerroa to North Durras within the Shoalhaven region of New South Wales. This is an area of 4,660 kilometres inclusive of 49 towns and villages ⁽³⁵⁾ and at 2007 a population of 92, 800 (36). Population growth is currently at 1.02% with the population expected to exceed 98, 000 by 2011 ⁽³⁶⁾.

Only consenting patients over the age of eighteen years of age, with intact cognition were to be included in the study. Patients receiving domiciliary oxygen as per the Thoracic Society of Australia and New Zealand Guidelines (TSANZ) ⁽¹⁵⁾ were eligible to participate in the study.

The study design excluded patients who were actively receiving treatment from the principle investigator. This was to ensure reduction in a perceived power relationship, and the possibility that participants may have responded to the semi structured interview prompts with a response influenced by any oxygen management advice previously given by the principle investigator.

Patients who were receiving domiciliary oxygen for palliative care reasons were excluded from the study, as their oxygen prescription may not be related to a respiratory condition, but comfort measures. Furthermore, it was deemed insensitive to invite this group to participate during their palliation. Patients receiving oxygen outside of the TSANZ guidelines, i.e. had purchased their own oxygen, were also excluded from the study.

A purposive sampling technique was employed for patient recruitment. Patient recruitment occurred via an independent third party (the oxygen clerk), who provided a list of potential candidates to another independent party (a physiotherapist) within the Shoalhaven Chronic Obstructive Pulmonary Disease (COPD) Service. Potential participants were cross referenced against the COPD database. Those who were not on the database or had not received

an intervention from the Shoalhaven COPD Service or the principle investigator within the last six months were invited to participate in the study. The final list of potential participants was selected by a clinical member of the COPD Service (not the principle investigator). Participants on the list were selected and grouped into batches of five to enable a timed approach to initial contact. Fifteen people using domiciliary oxygen were invited to participate from the batched groups of participants. Six of those contacted declined to participate in the study due to health reasons and one was found to be deceased. Two were unable to be contacted, despite mail and phone attempts and one potential participant was not interviewed as saturation had occurred at the fifth interview.

The initial contact letter (Appendix A) and patient information sheet (Appendix B), were sent to the potential participants. The initial mail contact was followed by a phone call, to determine if the participant wished to participate in the study. A date and time was negotiated to conduct semi structured interviews in their home at the participant's convenience.

An Occupational Health and Safety 'Home Visit Risk Assessment' was undertaken by phone, prior to the home visit, to ensure the safety of the principle investigator during the home interview.

Written consent was sought after explanation and the participant was provided the opportunity to ask questions. Each participant was provided with a copy of the consent and participant information sheet. Participants were informed that participation in the project was voluntary and they were free to withdraw from the project at any stage prior to final data processing and analysis. As data was de-identified, there would be difficulty withdrawing transcriptions from the cohort after data processing and analysis. Participants were informed that refusal to participate would not impact in any way upon their current or future health treatment needs within SESIAHS or the services of NSW Health.

It was planned to interview between six and ten participants; however saturation of themes/ideas occurred at the fourth interview. A fifth interview was booked and undertaken to ensure redundancy and no new ideas had occurred. A trial interview and pilot of the interview questions and a critique of the interview technique was undertaken on 27th August 2009, with a patient and his spouse who was well known to the principle investigator. Post interview discussion determined that the interview guide was appropriate and the principle investigator was able to adequately interview and was competent using the digital recording equipment. All interviews were undertaken by the principle investigator.

The semi structured interview in the patient's home or preferred place was the chosen design, due to the following:

- the patient's home provides a comfortable, safe place for the interview to take place

- to reduce any possible inhibition or bias associated with a hospital setting
- the best time for the patient recognising their clinical condition
- patient convenience
- lack of transport infrastructure within the rural Shoalhaven region
- asking the patient to travel with oxygen could pose physical and logistical difficulties

The patient's carer was able to be present at the interview and offer insight and support to the patient, if the patient chose.

An interview guide (Appendix C) was used as a prompt and to keep the interview on track, with questioning taking on a conversational aspect. Interviews were digitally recorded for transcription and electronically secured on the password protected drive within the Area Health Service.

Consideration was given to the well being of the participant and carer during the interview. It was thought the potential risks to the participants could include emotional distress or shortness of breath related to anxiety or whilst talking. Careful consideration was given to minimise these risks including a steady paced interview guided by the participant's rate, and time for the participant to articulate feelings.

Post interview, extensive field notes were documented in writing and via digital recording. Permission was sought from the participants to include this data within the analysis and all participants consented. A copy of the transcripts was available to participants, but all declined this offer.

Interview duration was from 28 to 32 minutes with mean interview time of 33 minutes. The total home visit time, inclusive of the interview was from 60 to 90 minutes with mean home visit time of 73 minutes.

As the principle investigator is a novice researcher, the first two interviews were reviewed by the principle investigator's research mentor to ensure thematic consistencies, prior to conducting the remaining interviews. Transcripts were analysed for emergent themes to enable the open coding process. This was followed by axial coding by organising the data to make connections between the main categories and subcategories. The main categories became the major themes of the study, comprised of the grouped subcategories. All coding and analysis was completed by hand.

Participant histories

A total of five participants undertook interviews within their own homes. Each of the interviews took place within the Rural Health Directorate, in the Shoalhaven LGA, on the NSW South Coast. The Accessibility Remoteness Index of Australia (ARIA) rating of 1.2 – 1.44 indicates that the area under study is classified as inner regional Australia ⁽³⁷⁾. The following provides a brief history

of each participant to help frame the context of the discussion. Pseudonyms are used to ensure confidentiality is maintained.

'Jan' is a 71 year old woman who lived in a two storey home with her husband, who is her primary carer. Her residential ARIA index is 1.16. The living areas were upstairs. Jan had been prescribed oxygen for COPD. Her prescription required her to use the oxygen sixteen hours per day, inclusive of overnight use. She sat at the kitchen table during the interview, without her oxygen on. Her oxygen concentrator was out of sight in a spare bedroom. Items that she uses regularly, such as the phone, medications, tissues and water were within arm's reach. Her husband was in the background and added to the interview. Jan didn't have access to portable oxygen, but was in the process of negotiating the rental of bottled oxygen to travel to an important family event in Canberra.

'Di' is a 53 year old indigenous woman who lived at home with her teenage daughter. Her residential ARIA index score is 1.2. She has an extensive cardiac and respiratory history inclusive of pulmonary hypertension. She uses oxygen via a concentrator at home and a continuous positive airway pressure (CPAP) machine at night for her concurrent sleep apnoea. She was resting on the lounge during the interview and didn't use any oxygen throughout the interview. She receives a home care package to assist with housekeeping, shopping and her exercise program. She has recently lost 63kg, but acknowledges that at 130kg, she still has some weight to lose. Her community care package enabled her access to bottled oxygen.

'Jacky' lives with her husband. The ARIA index of her place of residence is 1.44. She is an 81 year old woman who had her oxygen prescribed for COPD. Her interview took place at the dining table, under a closed in back verandah. She had her oxygen on during the interview; her concentrator was situated in the lounge room out of the way. Jacky has no access to portable oxygen. She had some essentials such as phone numbers, cordless phone, note book, tissues, nebuliser, and medications on a shelf nearby. A television was playing nearby, but muted during the interview. Jacky's husband was in the background and added information as the interview took place. Jacky receives home care to assist with the housekeeping weekly; otherwise her husband is her primary carer. They rarely go out and enjoy the company of each other.

'Joy' is an 87 year old woman who resides in an area with a residential ARIA index of 1.034. She was totally blind due to macular degeneration. She ambulated with a four wheeled walking frame, and whilst elderly was not frail. Her oxygen had been prescribed for COPD and nocturnal oxygen desaturation. She didn't use any oxygen during the interview and the concentrator was out of sight in her bedroom. Joy had no access to portable oxygen. The interview took place at the kitchen table, with her 92 year old husband, who is also her carer.

'Mike' is an 82 year old man who lived in a seaside village with an ARIA index of 1.3. He had oxygen prescribed for worsening COPD and has a concentrator, which was positioned in a spare bedroom. He has also purchased a portable

concentrator, which he keeps nearby the dining area on charge. His interview took place at the kitchen table and he didn't wear oxygen during the interview. He lives with his wife and they do not receive any home or community care.

Findings and Discussion

Three broad themes were identified after an analysis of the transcripts. Each theme comprised a set of sub themes.

The recurrent themes were

- Oxygen as an enabling paradox
- Oxygen as an inevitable necessity and
- Resignation and modification to accommodate changes in independence.

Theme One - Oxygen as an enabling paradox

Participants described that oxygen gives them their freedom, but is at the same time restrictive. The provision of oxygen made participants feel safe and feeling safe was an important factor for all of the participants. Travelling too far from home implied that access to oxygen was further away and this limited those without portable oxygen to travelling. The struggle for breath is explained as frightening and the availability of oxygen reassuring.

"I wanted to die because I had enough. I was fed up with struggling for breath. ...I was preparing to die to be honest. And even in the hospital I felt safe there with the oxygen there 24 hours, around the clock, yeah I do. I feel safe with it. Yeah. Safe, that's the word." Jan

"I feel that it was a good thing and I felt a lot safer knowing that it was in the home." Di

Oxygen was reported as improving energy levels, often due to reducing nocturnal hypoxia resulting in a good night's sleep. However the constant struggle for breath is explained as exhausting, so the energy gains from the oxygen were counteracted by the energy consumption of dyspnoea.

"You just go to sleep, but when you have oxygen, you wake up and you got, like, full of energy...it makes me feel better and I've got more life in me now than I would have ever had." Di

Participants reported that oxygen was helpful overnight to reduce daytime fatigue and drowsiness.

"...the oxygen gives me a good night's sleep...I put it on about ten and then I might, about five o'clock get up and go to the toilet and then I might take it off, for a little while, it all depends on how I feel. And then I don't get up until about nine o'clock." Jacky

“...so I have oxygen to help me breathe and sleep and I have it in the night time to keep me going. Without it I’m always napping out.” Di

Like former studies ⁽³¹⁾ participants in the current study reported having access to oxygen gave them confidence, energy and increased independence.

“...oh it has increased my independence. Oh well, I can walk to the letterbox now; I couldn’t do that before the oxygen; and I can do more things now. Well I couldn’t do anything before. I couldn’t wash up or do that.” Joy

“...it gives me confidence. Well I can move around, all of my movements were limited, I can move around without getting all puffed, gasping for breath.” Jacky

The provision of oxygen gave people more confidence, energy, improved exercise tolerance, reduced shortness of breath and subsequent fatigue. It was consistent across all participants that not having access to oxygen produced panic and anxiety, and made them feel scared and frustrated. The concept of the panic attack and dyspnoea was explained by all of the participants. It was described as frightening and self perpetuating. Shortness of breath was reported to lead to panic and as panic increased so did the shortness of breath.

“I get panicking and I get sweating and I get short of breath and it’s because I’m scared with the pains, I’m gunna have a heart attack or something. So I make myself worse than anything and I realise I can’t do this, gotta try to calm myself back down. So I sit there until it stops it or grab a book or something and try to calm myself down. Yep, I have my oxygen when I’m doing it. I put the oxygen on with the full face mask when I’m really scared.” Di

Oxygen was explained as helpful during a panic attack and made the dyspnoea/panic/anxiety cycle somewhat easier to manage.

“You just feel, like you are going to die, gasping and then as I say, I take control...it works. It doesn’t of course calm me down in total, OK, but it takes the panic away.” Mike

Lack of energy related to a poor night’s sleep resulted in frustration, as it was difficult to do anything during the day with depleted energy stores.

“I get frustrated. I can’t do nothing. You know. So if I lay down and get my oxygen and just relax...the shortness of breath and just that, I can’t do nothing all day. I can’t do anything.” Joy

Participants described oxygen as being restrictive, yet it enabled them the ability to manage ‘things’. This was the paradox of oxygen as an enabler. There were positives to having the oxygen but restraint at the same time.

“Oh, just being tied to a...being led by a tube. A bit like a dog on a lead.”
Mike

For some participants the relief that oxygen was available was seen as an opportunity for them to live longer and have some form of life regardless of the limitations attached to their disease or treatment.

“My life, um, without the oxygen I wouldn't have a life....I'd be gone. I'd be gone. See I got pulmonary hypertension or whatever it is and without the oxygen, it's given me back lots. It's given me back my life and given me longer for my daughter. Because there is me and my daughter and that's it.”
Di

“The benefit is it is keeping me alive and letting me be a little more mobile than I would have been.”
Mike

Participants acknowledged that portable oxygen is expensive and those with the means to independently purchase it were less restricted and able to socialise outside of the home. Those without access or means found oxygen acquisition expensive and elusive;

“I was buying oxygen in the big cylinder tanks and it nearly sent us to the poor house.”
Jan

“...the portable one is very good really. It costs a lot though. Five thousand dollars.”
Mike

Theme one findings have demonstrated how participants perceive that oxygen makes them feel safe, gives them confidence, reduces panic, increases independence and improves sleep. Inversely, lack of oxygen makes people short of breath which results in anxiety and panic, fear and fatigue. There was fear amongst oxygen dependant people that oxygen, or access to oxygen may be taken away by Area Health Services. There was also fear in how changes in the administrative process of providing oxygen may affect oxygen provision.

Those participants who had access to portable oxygen reported less restriction and isolation, but commented on the expense of portable oxygen. In a report by Crockett, Moss and Alpers⁽²⁸⁾, hospital budgets have been strained in the provision of oxygen concentrators to people with respiratory failure. The provision of portable oxygen cylinders to patients to enhance quality of life and improve mobility are reported to consume more than one third of health oxygen budgets.

Theme Two: Oxygen as an inevitable necessity

Participants were resigned to the need for oxygen as part of their treatment. This theme also explained how environmental factors affect shortness of breath and consequent oxygen use, how oxygen use physically affects people and how oxygen has become an intrinsic part of their lives.

Participants had anticipated using oxygen therapy due to their disease progression, worsening shortness of breath and limited exercise capacity. The participant's belief is that their lung disease is so severe they cannot maintain adequate oxygenation. By adding oxygen therapy, symptoms associated with poor gas exchange (dyspnoea) should resolve. Expectation of what oxygen could achieve was generally higher than what people experienced. Participants reported feeling relieved when they qualified for it, expecting that it would significantly improve their situation and that the constant struggle for breath would be over.

"Oh well, I was expecting it for some time. Um, disappointed a bit with what it did for me, I was expecting more...it doesn't help as much as I thought it would. Uh, it doesn't control your life. You can still do a certain amount. Not as much as you used too, and no need to think you are going to die before your time because you have oxygen"....."The benefit is it is keeping me alive and letting me be a little more mobile than I would have been."
Mike

With the anticipation of the oxygen as an inevitable part of the disease trajectory, there was also acceptance and resignation of the oxygen therapy.

"...it (the oxygen) was something I need to make life a little more pleasant. Oh, I continue on, I can't do anything about it. Why worry about things you can't repair."
Jacky

There was agreement across participants that heat and humidity adversely affected them and resulted in an increase in shortness of breath, fatigue and exhaustion. February was seen as the most difficult time of the year for shortness of breath;

"I just get tired or don't feel well and I feel too short of breath, because it is too hot outside and it is too humid and I get really short of breath fast, so I use the oxygen then and this is for me, I do this for me." Di

"...in this hot humid weather, oh that stuffs me totally. Ah, the difference on the first dry day. I walked to the mail place no trouble at all."
Mike

As previously studies had been undertaken in cooler climates, shortness of breath related to heat and humidity was not reported. Ring and Danielson (1997, p 341), described wintertime and bad weather with low temperature and low barometric pressure as being more restrictive, whilst Barnett (2005, p808) reported night time shortness of breath as being problematic. None of the participants in this study reported worsening symptoms in the winter months or nocturnal dyspnoea.

The actual use of oxygen was described as being problematic. Participants commented that nasal prongs caused intra nasal irritation, dryness described

as a burning and often blood clots would form in their nose which was difficult to remove.

“Sometimes it makes you really dry and your nose and everything dries up. I don’t know if it is me or from the oxygen, but it was. And it makes you wake up like you want to drink all night.” Di

There were also comments about the tubing being a trip hazard, particularly for the sight impaired using mobility aids and during the night when it is difficult to see.

“I’ve got it beside the bed and the cord reaches all the way out to the sunroom. The cord gets in the way sometimes especially with my walker. Sometimes I get tangled up in it”. Joy

Whilst participants acknowledge that oxygen enabled better sleep there were comments regarding disturbed sleep due to the oxygen tubing.

“It annoys me. Well, with the prongs up your nose, nostrils and then the tubing around your ears, it hurts sometimes, even if I loosen under here (points to under chin), you feel that the little prongs are coming out of your nose, so all night I feel that I’m adjusting it and you turn around and you gotta adjust it, throw the cord in the other direction. Yes, it can be quite annoying.” Jan

Participants described their oxygen as part of themselves and part of their lives. It was not only seen as a part of their treatment plan, but an extension of themselves, in a similar manner to glasses or dentures. Participants perceived they were actively managing their disease process with the use of oxygen. Conversely, if a participant were to feel that they were an extension of the oxygen this would imply that they were not managing their disease and were passive in the disease process.

“It’s something that is just part of life. And I find its part of life, part of me. It’s just like part of the family, I go anywhere, I need it, I take it.” Di

This is consistent with previous research⁽³⁸⁾ where the reference of a medical device as part of oneself would imply a successful device integration. The study also referred to the concept of device ownership equating to acceptance.

One participant humanised the concentrator by giving it a name and including it as part of the family with a specific role and purpose. The participant has attempted to humanise a mechanical device.

“Yes it looks after me. Yes it does. That’s my baby. My daughter gets cranky, because I call my machine Jess, Jessica. Because she (implying the concentrator) is part of my life, she’s like my daughter, so she is part of my family, and she’s there all the time, so she’s not going anywhere, so yeah, I call her Jess.” Di

Findings have shown how people anticipated oxygen as part of a chronic lung disease and resignation to and acceptance of oxygen was a natural progression in the disease process. There was disappointment that the oxygen didn't cure dyspnoea and exercise intolerance. Heat, humidity and anxiety and panic were elements which produced worsening dyspnoea and having access to oxygen during these times provided a sense of security. Participants were able to discern if oxygen or their disease was the disabler/handicap in their mobility and functional capacity. It was perceived that when oxygen is an extension of the patient, the patient is in control of the disease and inversely if the patient was an extension of the oxygen, then the disease is the master and the patient would be seen as the passenger in the disease journey. If oxygen is what enables the patient to live, removal of oxygen would implicate (the sensation of) impending death.

Theme Three: Resignation and modification to accommodate changes in independence

Participants had accommodated and made changes in their lives to be able to manage their declining health. Participants discussed physical and social isolation. All reported that disease progression and decreased energy caused constraint to socialising outside of the home. The availability of portable oxygen enabled the participant to move outside of the home with more confidence (and self reported 'safety'), although not having access to portable oxygen didn't isolate the patient, but did make travel away from the home more inconveniencing and fatiguing. Participants used other strategies when away from oxygen to help them manage their shortness of breath.

"It certainly lets me go out, long distances and short distances. Yeah, independence, well the portable certainly increases it."
Mike

Access to portable oxygen was not an inhibitor for some and they used novel strategies to help with their dyspnoea when away from home and their oxygen.

"We might go out for the day. Oh sometimes I take my nebuliser. I take my nebuliser when I go, I take my nebuliser." Joy

Participants commented on the modifications they had made to their lives to maintain their social connectedness to the world. Some used the phone and the internet as a means of maintaining contact with friends and family.

"I've just got accept it. I don't brood about it all the day. I play on the computer quite a bit, crosswords and keep my brain, what's left of my brain going around a bit." Mike

One participant reported not ever being a sociable person anyway, so their lung disease had little impact in that area.

"...no, I don't feel isolated because of the oxygen. No. I like our own company. The company of my husband and myself...I

keep in contact with the family by phone. They call each week; on a Sunday.” Jacky

Another participant had friends and neighbours visit regularly, and maintained contact with others by phone or mail. She reported feeling well supported by her family and friends.

“Oh yeah, one lady, my neighbour down there, she comes up and we play scrabble of an afternoon, so that’s good too... Oh the phone never stops, um, I’ve been a fairly popular person...and when I was in hospital they put a sign on my door...too many people are coming to visit me...everyone that knows me appreciates what my complaint is and you know everyday I got heaps of get well wishes, you know, out of the mail, and Bob would bring them to me, and yeah, that makes you feel very much loved.” Jan

Social networks have been found to be associated with resilience in previous research⁽³⁹⁾ and a sense of belonging found to support health resilience⁽⁴⁰⁾.

Participants reported how they had modified some of their activities to be able to tolerate their worsening lung disease and increased breathlessness, by decreasing their oxygen demands. One participant explains the fight, a battle with her shortness of breath, as if survival is a war against dyspnoea and her strategy to manage this.

“I was doing great battle, and I mean I was battling; I was punishing my lungs, to the most, coming up the stairs. And I thought, ‘I won’t be able to leave this house the way I’m having to contend with the stairs. And I didn’t realise it, a dear friend of mine gave me a wheelchair and it’s downstairs. So now Bob brings it to the bottom of the internal stairway, he pushes me over there in that (points to the four wheeled walker), and I just take my time, step by step, and if I puff out I stop and have a rest and take a few more steps, and then he pushes me all the way through downstairs, till I get in the car and rest again. We shoulda been doing that a long time ago”. Jan

All participants acknowledged the loss of their former selves and articulated their feelings of grief. This was supported by the previous studies in people with chronic disease and using oxygen.

“I just thought I’m not the same person as I used to be and I’m not going to be able to do the things I used to do and I haven’t been able to do the things I used to do. And so I thought, mmm, strong me who’s been very strong willed, when I don’t want this to be happening to me. And I’m not blaming the oxygen for that; I’m blaming my diseased lungs that are doing that.” Jan

The quote above demonstrates both grief and blame, as diseased lungs and oxygen has reduced the person from a whole person to a discounted one ⁽³²⁾. In an unpublished 2006 study by Crockett, et al⁽³²⁾ participants' experienced a sense shame as their lung disease was self inflicted. By dissociating themselves from their lungs they are in effect blaming their lungs and not themselves for their current health situation.

The feelings of not being able to contribute to the family and grief for the loss of their former self were explained consistently and were supported by the findings of other studies. Being able to maintain the home to the same standard as in years past was seen by all participants as important. Not being able to contribute to the family unit by way of housekeeping left the participants feeling redundant within the family unit.

"I love to keep the house tidy and clean, I love to be in and out of cupboards all day long. I love to do these things and I can't do them anymore. Because when you're active and then suddenly you can't do anything, um, you feel useless, you feel useless. You know I'm always saying to him 'I'm sorry'. Yeah. You feel useless." Jan

"Oh well, you are missing out a lot, but then as I say there is not a lot I can do about it. Well not being active, not doing more, not um, for instance, Jim used to do the vacuuming and I used to wash the floors. Well I don't do that. I used to do the cooking. Well I don't do that. I feel a bit useless, but there's not much I can do about it." Jacky

Whilst the use of the word *useless* was frequent amongst participants, post interview, four of the five participants gave the principle investigator a guided tour of their homes and their lives. These four participants were coincidentally not wearing oxygen during the interview. This behaviour reinforced the health related stigma concept ⁽⁴¹⁾. Health related stigma is a social process where people have felt excluded, blamed, devalued or rejected on the basis of a feature of themselves, in this case a smoking related lung disease and oxygen usage. During the tour, participants' delighted in exhibiting their craft, their skills and the achievements of their former lives, indicating a strong desire not to be judged as a worthless component of their disabilities, but holistically, as a valued contributing member of the community.

Participants demonstrated feelings of grief at the loss their former self and felt useless at not being able to do what they had previously been able to do prior to their disease. Interestingly, the participants acknowledged that it wasn't oxygen that constrained them but their disease.

"I don't blame the oxygen for that. I mean, that is there to help. My condition makes my lungs this way." Mike

Khalili, (2007, p 5 – 6), reports that throughout the illness trajectory people face issues of fear, uncertainty and hope. Throughout each illness transitions or stages there are losses and gains to which the person adapts. This is

evidenced in the participants' comments of how they cope with each new level of disability within their disease trajectory⁽⁴²⁾.

Participants considered perceptions of others in relation to their oxygen. All participants stated they were not overly concerned with the impressions of others, and felt that the oxygen was no more than a type of aid to help them be able to move around the community better.

"I have noticed some people trying not to look. But uh, no that doesn't worry me...there are people with wheelies, all sorts of things around and trolleys and God knows what, so what is the difference?"
Mike

One participant made observations regarding the thoughts of others, that there may be fear associated with the flammability of the oxygen and concern that today's smokers may be tomorrow's oxygen dependent person.

"Well some people look at you like, you are stupid, when you are walking around with that (pointing to the portable oxygen cylinder), near the cigarettes, or something. Because when you go to the back of Coles, people all smoke, so you gotta try to move around to try to get in. They can see you coming with the oxygen thing and they don't pay any attention, they stand there and still smoke. And I think they don't like it. Because I think to them it looks like it's difficult or there is something the matter with that woman or something and it's saying, OK, she's a danger because she has got that on. That's what they are saying. They are scared that it is gonna blow up when they are around it or they are scared they are gonna end up with the same thing."
Di

Findings show that participants believed that oxygen had increased their independence and that access to portable oxygen enabled the freedom to choose different activities away from the home. However, without portable oxygen participants still managed to move out of the family home, more slowly and with more symptomatic restrictions. Those without access to portable oxygen had adopted other means to reduce their shortness of breath, such as breaking down tasks into smaller steps to reduce oxygen demands and the use of a nebuliser. Those without access to portable oxygen chose to limit the distance that they were away from home, where their concentrated oxygen was. They reported that, without portable oxygen it may be 'risky' being too far from home.

Participants had found other means of maintaining social connectedness within their limitations with the use of phone and computers and regular visitors to their homes.

Participants were accepting of their oxygen as an inevitable part of treatment in their disease progression. They described relief that 'lung help' in the form of oxygen had 'arrived' but disappointment that it didn't do what they were expecting it to. It was interesting to note that throughout all of the interviews only one participant was wearing oxygen and all of the oxygen concentrators were out of sight. Whilst all participants acknowledged relief that they had, when prescribed oxygen, the sight of the concentrator was a visual representation of the severity of their lung condition.

While all participants expressed no concern of others' perceptions of their oxygen, the behaviour of not using oxygen during the interview for four of the five participants would indicate the health related stigmas associated with oxygen use ⁽⁴¹⁾. Stigma is associated with health conditions outside of 'normal' and is defined as feelings of shame, rejection, blame and devaluation ⁽⁴¹⁾. Previous experience of discriminatory social judgement about a person with oxygen may have been the reason for participants not wearing oxygen during the interview.

From the above it can be seen how the participants in the study demonstrated resilience despite their poor health and rurality. Resilience is described as a factor which helps adults adjust with the hardships associated with aging and disease. Both physical and mental health status positively correlate with resilience with mental health status being the stronger predictor of resilience ⁽³⁹⁾. The participants in this study, despite poor physical health, had positive attitudes and outlook on life and appeared determined to manage their disease within their limits. Rural areas demonstrate a higher level of social capital than urban areas ⁽⁴³⁾. Social capital is described as a ecological construct which includes "social trust, reciprocity, cohesion and participation and a sense of community" ⁽⁴³⁾.

Findings of the study consistently demonstrated that despite poor health and oxygen dependence participants did not report social isolation as was reported in previous studies. The resilience and social capital of the participants enabled strategy development to assist with dyspnoea, panic, access to portable oxygen and activities of daily living. However, all participants confirmed the findings of previous studies in relation to grief/loss of their former self and whilst oxygen dependent, attributed their situation to their lung condition not the oxygen therapy.

Limitations to the study

The small sample size and the exploratory nature of the study limits the generalisability of the results. The study considered people using oxygen in a rural setting, but the data obtained could not be extrapolated to infer an understanding of people with domiciliary oxygen in a remote setting. There is debate regarding what constitutes rural as opposed to urban and some definitions ⁽⁶⁾ would consider the geographic area as more urban than rural.

Participants in this study were those that met the qualification standards for domiciliary oxygen as per the TSANZ criteria. Some patients who do not qualify by the criteria purchase oxygen at their own expense, as they perceived their symptoms severe enough to warrant the investment. It is unknown to the health services how many people in the community are in this situation and this privileged information is only accessible via the oxygen providers. Findings from the present study are not generalisable to this patient group.

Whilst all care was taken to ensure participants did not have a recent health intervention with the principle investigator, a previous intervention of several years past may still have had an impact upon the participant and affected their response.

Whilst the researcher has a raised awareness of preconceived beliefs and opinions about the phenomenon under study, there may still be an element of bias as the interviewer reacts to responses from the participant ⁽⁴⁴⁾. The investigator considered self bias and attempts were made to bracket preconceived ideas with the use of a reflective journal throughout the research process.

The sound methodological approach and response rate with early saturation of ideas was a strength of this study.

Conclusions and recommendations

This study has demonstrated that people living in a semi rural location, report that oxygen enables them to feel safe, reduce dyspnoea, panic and anxiety and improves energy levels. At the same time as there are benefits to oxygen it is also reported as being annoying and inconveniencing, and its use in the home tethers the user to a machine.

Social and physical isolation were not reported by participants who had access to portable oxygen either in the form of cylinders or portable oxygen concentrators. Participants without access to portable oxygen tended not to travel far from home and when they did used strategies to minimise oxygen consumption and shortness of breath.

This study raises awareness for health care providers and policy makers of the difficulties people living with respiratory failure and oxygen therapy encounter. For the patient, panic, dyspnoea and oxygen availability are all real fears. The availability of portable oxygen makes the ability to socialise within the patients' physical means more attainable; however this luxury is currently limited to those with financial means. Chronic lung disease is a smoking related disease which is associated with those from a lower socio-economic group, where access to portable oxygen for most is unattainable. Policy makers should consider the provision of portable oxygen to oxygen dependant people not as an ancillary service but as intrinsic to the care for this socio-economically disadvantaged group. Means testing doesn't currently apply to life saving

devices such as pace-makers; income testing on oxygen should be reviewed to ensure device equity.

Currently an Australian Standard exists for the implementation of strategies such as ramps and ramp gradients for wheelchair bound disabled persons. There needs to be a similar standard developed for persons who have a hidden disability related to medical conditions that require frequent resting. The strategic placement of resting chairs in public areas would help improve the ability of people with a hidden disability to be able to participate in the community.

This study has demonstrated perceptions of people using oxygen from an ARIA inner regional Australia defined area. Further studies using a similar methodology would be encouraged using the ARIA index to interview patients in outer regional, remote and very remote Australia, to determine the association between resilience and social capital in these communities where people use domiciliary oxygen as part of their medical care.

Participants described weather conditions that adversely affected their symptoms. Further study regarding humidity, temperature and barometric pressure fluctuations would add to the body of evidence surrounding factors which precipitate symptoms. The findings of such a study will have implications for clinical practice; the results will enable patient education and action plan development that incorporates variables such as weather and seasonal changes.

Whilst the suffering of dyspnoea has been explained by participants with chronic respiratory disease, there is an opportunity to consider that patients with palliative conditions that require domiciliary oxygen could have similar experiences with the oxygen aspects of their disease and is worthy of future study.

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Initial contact letter

Date: _____

Dear _____,

You are invited to participate in a research study investigating the perceptions of patients who are using domiciliary (home) oxygen as part of their medical treatment.

The study is being conducted by Tod Adams, who is a Clinical Nurse Consultant at Shoalhaven Hospital, part of the South Eastern Sydney Area Health Service (phone 44239705).

Please find attached a participant Information sheet that will provide more information about the study.

In a few days Tod Adams will ring you to see if you are interested in participating in the study.

If you do not wish to be part of this study just let us know when you are rung - you do not have to give a reason if you do not wish to participate.

Kindest regards

Tod Adams
Clinical Nurse Consultant II
SDMH
Po Box 246
Nowra NSW 2541



PARTICIPANT INFORMATION SHEET

Patient's perceptions of domiciliary oxygen in the rural setting.

Invitation

You are invited to participate in a research study investigating the perceptions of patients who are using home oxygen as part of their medical treatment.

The study is being conducted by Tod Adams, who is a Clinical Nurse Consultant at Shoalhaven Hospital, part of the South Eastern Sydney Area Health Service (phone 44239705).

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

1. 'What is the purpose of this study?'

The purpose is to investigate how people who are using oxygen feel about it and what it is like to live with oxygen from your point of view.

2. 'Why have I been invited to participate in this study?'

You have been invited to participate because you have oxygen at home as part of your medical condition and live in a rural area.

3. 'What if I don't want to take part in this study, or if I want to withdraw later?'

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide **not** to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with The South Eastern Sydney/Illawarra Area Health Service, Shoalhaven, Milton or David Berry Hospital or associated community health centres within the Shoalhaven region.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. However, it may not be possible to withdraw your data from the study results if these have already had your identifying details removed: the researcher will be happy to discuss this further with you if you wish, before you give consent.



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ILLAWARRA**
NSW HEALTH

4. 'What does this study involve?'

This study will be conducted at your home and will involve a taped interview with you. The interview will last for about one hour. The study itself will run over one year and is due for completion in June 2010.

If you agree to participate in this study, you will be interviewed in your home.

Prior to the interview:

- You will be contacted by phone and a few questions will be asked about your home to ensure the safety of the researcher
- A date and time convenient to you will be organised between you and the researcher

Prior to the interview a brief discussion will occur between you and the researcher about the research process. It is important that you feel comfortable during the interview, so it is best to choose a time of the day when you feel at your best.

If you wish to participate you will be asked to sign a consent form; this will be clearly explained to you by the researcher and the form will be provided for you to sign on the day. Any questions you have about the project can be discussed with the interviewer on the day. The signed consent form will be retained by the interviewer and you will be provided with your own copy of the consent.

5. 'Will I benefit from the study?'

This study aims to further our knowledge about how patients feel about using oxygen as part of their treatment plan for chronic lung conditions.

Although the study is unlikely to benefit you directly, benefits from this study are likely to be seen in the future through discussion, publications and further research into this area.

The study may benefit you by enabling you to share your views and feelings.

6. 'Are there risks to me in taking part in this study?'

If you decide to participate in the study, you need to be aware that the interview will take about 1 hour of your time.

The researcher/study team has taken steps to minimise any risk to you by protecting your privacy by de-identifying data, so you will not be linked personally to any of the data collected.

As with any research, there may also be risks associated with the research that are presently unknown or unforeseeable.



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NSW HEALTH

7. How will my confidentiality be protected?

Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researchers named above will have access to your details and results that will be held securely at Shoalhaven District Memorial Hospital in Nowra NSW.

8. 'What happens with the results?'

If you give us your permission by signing the consent form, we plan to discuss the results at conferences and scientific meetings and publish the study results in peer reviewed professional journals.

In any publication, information will be provided in such a way that you cannot be personally identified. Results of the study will be provided to you, if you wish.

9. 'What happens if I suffer harm, injury or complications as a result of the study?'

If you suffer any harm or complications as a result of this study, you should contact the researcher as soon as possible, who will assist you in obtaining appropriate counselling or treatment.

10. 'How is this study being paid for?'

The study is being sponsored by The Rural Institute of Clinical Services and Teaching as part of the Rural Research Capacity Building Program.

All of the money being paid by the sponsor will be deposited into an account managed by South Eastern Sydney Illawarra Area Health Service. No money is paid directly to individual researchers.

11. 'Will taking part in this study cost me anything, and will I be paid?'

Participation in this study will not cost you anything apart from your time, for which we thank you. You will not receive any monetary payment.



12. 'What should I do if I want to discuss this study further before I decide?'

When you have read this information, the researcher, Tod Adams will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact her on 02 44239705.

13. 'Who should I contact if I have concerns about the conduct of this study?'

This study has been reviewed by The University of Wollongong and South Eastern Sydney Illawarra Area Health Service Human Research Ethics Committee. If you have any complaints about the conduct of this study you should contact the University of Wollongong Ethics officer who is the person nominated to receive complaints from research participants.

The Ethics officer can be contacted on 02 42214457 or
The University of Wollongong and South Eastern Sydney Illawarra Area Health Service Human Research Ethics Committee
Research Services Office
University of Wollongong
Level 1, Building 20,
Northfields Avenue
Wollongong NSW 2522
Tel 02 42214457

Thank you for taking the time to consider this study.

This information sheet is for you to keep.



Interview Guide

Patient's perceptions of domiciliary oxygen in a rural setting – a qualitative study

Semi structured interview – try to cover following topics, but follow leads as they arise.

Ethics requirements

The purpose of this interview is to explore your experiences as a person using oxygen therapy as a treatment for your medical condition.

Your participation in the study is entirely voluntary and you have the right to withdraw from the study at any time. If you decide not to participate in this study or if you withdraw from the study, you may do this freely. You are free not to answer any questions you may choose. I am only noting the date of the interview. Any reports, papers or discussions with others will be confidential and no identifying information will be revealed to anyone outside the research team.

I would like to electronically record this interview so I can concentrate on our conversation instead of taking copious notes. The interview will be transcribed verbatim to make sure all of the discussion is accurate and complete.

Are you willing to have me electronically record our conversation?

Yes **No** (please circle and researcher to initial)

Are there any things you would like to ask me about this project?

Yes **No** (please circle and researcher to initial)

(2 consent forms provided – one for patient to sign and return to researcher and one for patient to keep)

Identifying data

1. Date of interview: _____

Leading questions:

- Can you describe for me the events that lead up to you receiving oxygen at home?
- How did you feel about that?
- What are the good things (positive aspects) and bad things (negative aspects) about starting on oxygen at home?
- How has your life changed as a result of starting on oxygen therapy?

Further Themes to be explored

Feelings of oxygen therapy

- *Dependence/independence* – Does oxygen increase/decrease your independence? In what ways?
- *Loss of body image* – How do you feel about your physical well being since starting on oxygen? Why is this important to you?
- *Isolation* – physical, social, environmental – Is it easier to get out and about with oxygen or has it been a hindrance to your social activities? How do you feel about this?

Quality of life

- *Dyspnoea* – Has oxygen use influenced your shortness of breath? In what way?
- *Emotional function* – How do you feel you are coping emotionally since starting on the oxygen? Has this changed over time? How do you feel about it now?
- *Fatigue* – Do you think your energy levels have changed since starting on oxygen therapy? What can you do now that you couldn't do before?
- *Mastery* – How do you feel you are coping with the oxygen? What is difficult about using oxygen?

Beliefs of oxygen therapy

- *Benefits* – What are some of the benefits for you when using oxygen?
- *Disadvantages* - What are some of the disadvantages for you when using oxygen?

Attitudes of oxygen therapy

- *Attitudes of others* – What do you think other people think about oxygen use? What have other people commented to you about oxygen use? What sort of things did they say? How did this make you feel?
- *Own beliefs* - What do you think oxygen means as part of your disease?

Determinants of 'dose' of oxygen therapy

- *What rate? How long? When?* How often do you think you should use your oxygen? Do you use it at certain times? What factors determine how long or how much oxygen you use? What factors influence when you don't use oxygen?
- *What sort of activities?* What tasks do you do that are easier when you use oxygen? Do you sleep with your oxygen on? (yes/no/why?)
- *Nare/nose care* - How does the oxygen affect your nose?

Are there any other things about oxygen use that you would like to tell me about?