

Adapting to domiciliary non-invasive ventilation in chronic obstructive pulmonary disease

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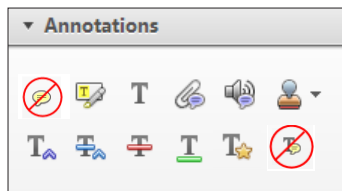
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Adapting to domiciliary non-invasive ventilation in chronic obstructive pulmonary disease: A qualitative interview study

Palliative Medicine

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Abstract

Background: Domiciliary non-invasive ventilation may be used in palliative care of patients with chronic obstructive pulmonary disease, although there is uncertainty regarding effect on quality of life.

Aim: Explore experiences of domiciliary non-invasive ventilation in chronic obstructive pulmonary disease, to understand decision-making processes and improve future palliative care.

Design: Qualitative interview study, based on constructivist grounded theory, and using the framework method for data management and analysis.

Participants: 20 chronic obstructive pulmonary disease patients, 4 carers and 15 healthcare professionals.

Results: Most patients had very severe chronic obstructive pulmonary disease. Data were categorised into four domains – clinical, technical, socio-economic and experiential. Healthcare professionals felt uncertain regarding clinical evidence, emphasising social support and tolerance as deciding factors in non-invasive ventilation use. Conversely, patients reported symptomatic benefit, which generally outweighed negative experiences and led to continued use. Healthcare professionals felt that patients chose to be on non-invasive ventilation; however, most patients felt that they had no choice as healthcare professionals recommended non-invasive ventilation or their poor health mandated it.

Conclusions: Our study identifies ‘adapting to non-invasive ventilation’ as the central process enabling long-term use in palliative care, although the way in which this is approached by healthcare professionals and patients does not always converge. We present ideas emerging from the data on potential interventions to improve patient experience and adaptation.

Keywords

Chronic obstructive pulmonary disease, non-invasive ventilation, qualitative research, domiciliary care

What is already known about the topic?

- Domiciliary non-invasive ventilation may aid survival in chronic obstructive pulmonary disease, but evidence pertaining to improvement in quality of life is inconsistent and could be a barrier to use in palliative care.

What this paper adds?

- Recommendations to optimise adaptation that emerged from our data include multi-modal education about non-invasive ventilation and community involvement in non-invasive ventilation care delivery.

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Implications for practice, theory or policy

- Service designs that better facilitate adaptation through education and practical support could aid use of domiciliary non-invasive ventilation in palliative care.

Introduction

Non-invasive ventilation (NIV) is used to treat type 2 respiratory failure and can be used acutely in hospital,¹ where it has clear benefits, or at home, where use is increasing as NIV machines have become cheaper and easier to use² but the case for use is less clear. In chronic domiciliary use for chronic obstructive pulmonary disease (COPD), some studies have shown benefits on mortality^{3,4} and admission rate,⁵ but this is not consistent. A recent Cochrane review showed no significant difference in quality of life (QOL) when used in such patients, and few other clinically significant benefits.⁶

In the United Kingdom, 11% of hospitalised COPD patients require NIV acutely;⁷ some may be unable to wean from NIV and thus require domiciliary use.^{8,9} Domiciliary NIV may also be started to prevent recurrent admissions,⁹ or in palliative care of patients with chronic respiratory failure.¹⁰ Palliative care for COPD is a recognised area of unmet need,¹¹ and very few qualitative studies exploring treatments used at this stage have been conducted. One of the larger NIV trials demonstrated improved short-term survival but decreased QOL;¹² this could occur because NIV is seen as inconvenient, uncomfortable or noisy. Given the inconsistent evidence from questionnaires used in trials, we chose a qualitative study design, aiming to examine the processes and experiences surrounding starting and managing NIV from the perspective of healthcare professionals (HCPs) and COPD patients with a view to designing future services capable of aiding patient tolerance/adherence and reducing any impairment in QOL.

Methods

Study design and ethical considerations

A qualitative interview study, approved by local ethics committee (11/WM/0422), was conducted over a 4-month period in 2012. Written informed consent was taken from participants; 1 of 22 patients approached refused to consent, and none withdrew consent. One patient was excluded as their treatment was found to be CPAP and not NIV. The remaining participants were HCPs or carers of the patients.

Recruitment and sampling

Participants were recruited using purposive sampling. We aimed to conduct 30 interviews, as prior experience has shown this sufficient to gain meaningful insights in applied qualitative health research, but this was later expanded to address emerging themes in the data. Patients

were identified by clinical teams. Inclusion criteria were as follows: COPD, past or current use of domiciliary NIV or at least two episodes of acute NIV use. The latter group was chosen as potential future domiciliary NIV users.¹³ Exclusion criteria included clinical instability or lack of mental capacity. All patients were told they could invite a carer to be interviewed; this was done to gain perspective on the contributions of carers to delivery of NIV and ascertain whether patients felt their carers' input was necessary to continue use. HCPs were recruited if they had experience of initiating or managing acute or domiciliary NIV in COPD patients. The interviewer (M.J.), a female medical student, was not known to participants prior to the study, had qualitative interview technique training as part of her research degree and was mentored by N.K.G. and A.M.T. during the process.

Data collection

Audio-recorded, face-to-face qualitative interviews were conducted in the interviewees' preferred location (patients'/carers' homes or at a hospital) by M.J. Interview schedules were prepared in advance by M.J., N.K.G. (medical sociologist) and A.M.T. (consultant respiratory physician), covering general views on NIV, decision-making processes to commence domiciliary NIV and experiences of long-term NIV use (supplementary data). Field notes were taken during interviews to aid subsequent interpretation.

All patients also consented to data collection from their hospital records. This was done to improve transferability¹⁴ of findings and gauge the typicality of participants. Direct questioning established MRSA, spnoea and Lawton Instrumental Activities of Daily living scores.¹⁵ No follow-up interviews were conducted and there was no participant input to transcription/correction of recordings.

Analysis

Interviews were transcribed verbatim and analysed descriptively using conventional (inductive) qualitative content analysis¹⁶ (Figure 1). Open coding was applied to transcripts, line-by-line, independently by both N.K.G. and M.J. without the aid of qualitative data analysis software. Inductive codes were created for patient interviews while both inductive and deductive codes were used to analyse HCP interviews. A descriptive coding framework was developed and agreed; concepts were grouped and summarised in a matrix using the framework method.¹⁷ Descriptive themes were developed from the data and

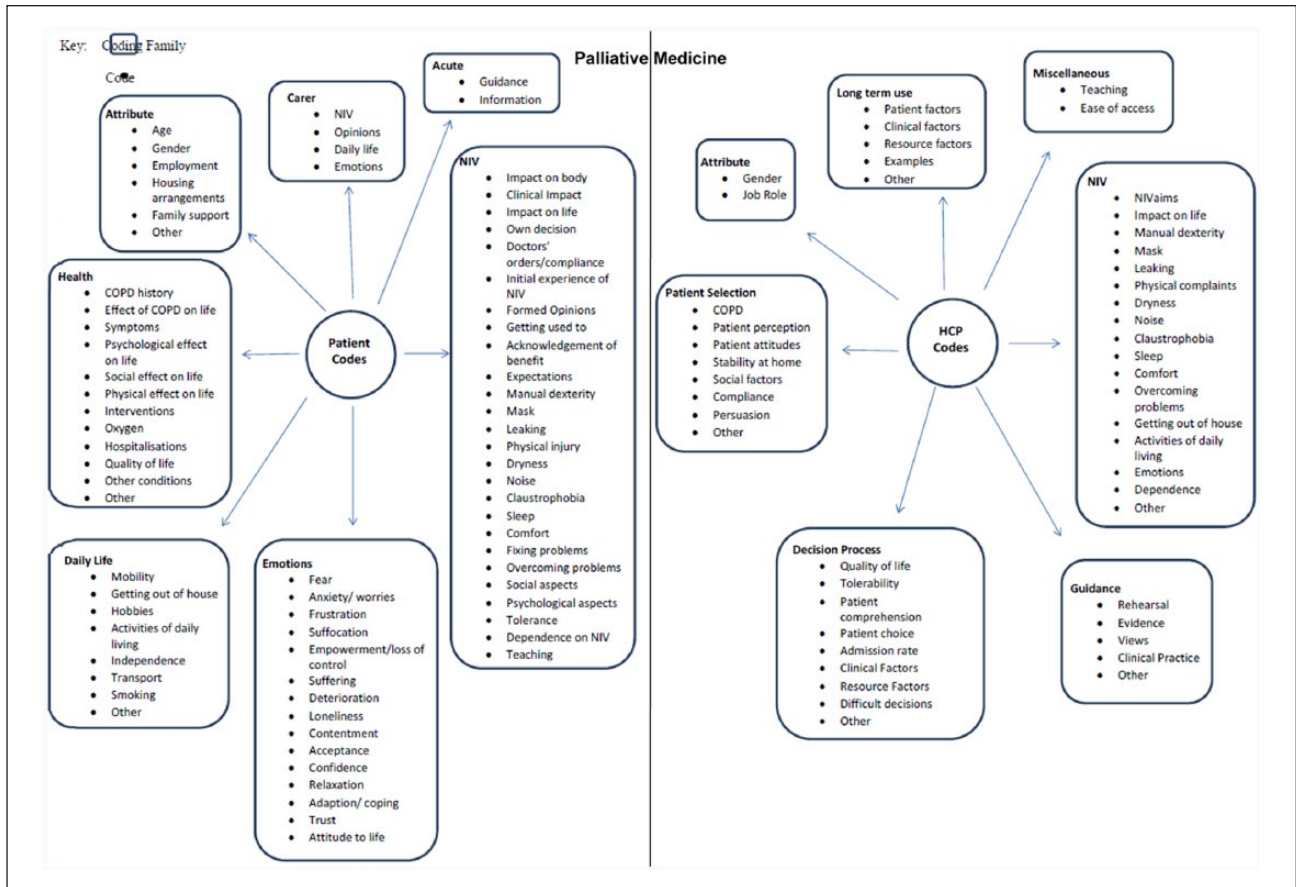


Figure 1. Coding framework used in data analysis.

deviant cases identified. Subsequent interpretive thematic analysis, based on constructivist grounded theory, was conducted focusing on 'social actions'.¹⁸ The central substantive theory that was developed and is described herein was 'adapting to domiciliary NIV'. Key findings are reported with illustrative quotes using anonymous identifiers: HCPs [HCP#], patients [P#] and carers [C#].

The above codes were used during analysis of patient (and carer) transcripts and HCPs, respectively. Several types were used including 'in-vivo', attribute, emotions, values, description or magnitude codes, the aim being to highlight a range of issues identified in the transcripts, allow meanings to develop and to be attached to the data. From these, the major and minor themes listed in Table 2 emerged.

Results

Participant characteristics

In all, 39 participants were recruited from two hospitals in Birmingham, UK. Characteristics of the patients ($n=20$) are shown in Table 1; 12 were chronic users of home NIV, 3 past users and 5 recurrent acute users. Patients had very severe symptomatic COPD, a high burden of COPD-related co-morbidities and high disability scores. Two past

users stopped due to intolerance, one due to receipt of a lung transplant. The data concurred with the literature showing the negative impact of COPD on patients' lives.¹⁹ Five patients lived alone with no daily carer; four had current daily carers (three spouses and one sibling) who agreed to interview; no other carers were willing/able to be interviewed. Carers were similar in age to patients, were generally well with few active health problems and no significant disability and shared patients' views of COPD. All patients and carers were White British or Irish.

The 15 HCPs recruited comprised 7 doctors, 4 specialist nurses, 2 physiotherapists and 2 physiologists. HCPs were aged 26–54 years and were predominantly UK born and educated, with a range of ethnicities. There were no notable differences in the themes emerging from different HCP types. Interview duration averaged 40 min (range 19–68 min).

Negotiating domiciliary NIV use

Decisions regarding domiciliary NIV were reportedly based on unclear clinical evidence, influenced by past experiences and individual negotiations. The social actions undertaken to assess whether a patient was offered domiciliary NIV and was likely to 'comply', as well as actions

7 8 **Table 1.** Characteristics of patient population.

Characteristic	Count (%) or median (range)
Male:female	8 (40):12 (60)
Age (years)	68 (52–83)
BMI	28.5 (17.9–47.0)
Years since diagnosis	8 (4–20)
% Predicted FEV ₁	27 (18–66)
Pack years smoked	63 (4.3–132)
PaO ₂ (kPa)	7.48 (6.49–10.8)
PaCO ₂ (kPa)	7.17 (5.51–11.4)
NIV	
Months of use	17 (0.2–140)
Hours/day	7 (2–24)
IPA ₁	18 (12–25)
EPA ₁	5.5 (4–9)
Nocturnal use only	15 (75)
Full face mask	19 (95)
Nasal mask	1 (5)
LTOT	15 (75)
Number of daily carers	1.5 (0–7)
COPD-related co-morbidities	
0	1 (5)
1	7 (35)
≥2	12 (60)
Lawton IADL	4.5 (1–8)
MRC score	4.5 (1–5)

BMI: body mass index; NIV: non-invasive ventilation; LTOT: long-term oxygen therapy; COPD: chronic obstructive pulmonary disease.

All data are shown as median (range) except gender, day/night NIV use, LTOT and COPD-related co-morbidities which are shown as n (%). Blood gas values are from the outpatient setting, while using NIV/LTOT in their usual manner (if applicable).

that patients took to decide whether they accepted and continued it have been categorised into four themes: clinical, technical, socio-economic and experiential. Table 2 provides a list of social actions (gerunds) identified in the analysis, grouped thematically, and provides illustrative quotes. It demonstrates clearly where views and experiences of HCPs and patients contrasted. Table 3 shows areas that emerged from the analysis that could be the focus of future care redesign. All themes contributed to the evidence pertaining to patient selection; technical and experiential themes were informative regarding mechanisms to improve tolerance/adherence and the socio-economic theme informed suggestions about health service designs supporting NIV use.

Clinical domain

The focus for HCPs was addressing clinical indications and improving outcomes. They felt limited by the absence of clear evidence on measurable benefits (e.g. hospital admissions, mortality), thus selected for treatment on a case-by-case basis. They described the importance of

taking time to convey the purpose of NIV to patients, to promote patient choice and to support compliance. HCPs tended to stress that the decision was ultimately the patients'; conversely, patients felt they had no choice about whether or not to accept domiciliary NIV, relying on their doctors' recommendations, believing they would act in their best interests. Nevertheless, many patients linked their acceptance of NIV with wanting to extend life and improve QOL.

QOL. HCPs acknowledged that they struggled with the potential for NIV to impair QOL and balancing this with uncertainty of clinical effectiveness:

If someone is really terminal COPD are you really going to do them any good by sticking them on a machine which might make their quality of life worse and they will probably die anyway whether you give them NIV or not. So the patient selection should be looked at very well before we start it on everyone [HCP #12].

Patients, however, were almost unanimous in their view that QOL improved with the use of home NIV, stating 'it has given me quality of life' [Pt #8]; 'It's done me proud' [Pt #1]; 'It's done me the world of good' [Pt #6]; 'It might be because of this machine I haven't been so ill' [Pt #10] and 'It has helped me and I am grateful of it' [Pt #19]. One patient was convinced that NIV was the reason she was alive; 'it was beneficial to me; it kept me going for 10 years ... that was quite an achievement' [Pt #1]. Many patients while acknowledging the medical purpose of NIV, to 'get the carbon dioxide out of the system' [Pt #10] and 'open up all the airways' [Pt #17], were also able to delineate specific symptomatic benefits. Patients experienced improvements in breathlessness, 'it helps me breath' [Pt #8] and in their general well-being, 'gives me a bit more energy' [Pt #1]. Patients also conveyed that NIV was helping them carry out their activities of daily living 'to do more' and 'get around more' [Pt #10]. Ultimately, this helped them to 'give me back a normal life ... to get me back to a normal existence' [Pt #1]. Carers also shared the same thoughts, revealing how they thought again it was 'a God-send' [C #8].

Socio-economic domain

Challenges of maintaining equitable care due to social deprivation were raised (e.g. failure to engage due to transport costs) as well as the potential for primary care involvement to improve management (Table 2). Some did not focus on equity, but felt it important to ensure that resources were not wasted. Generally, HCPs considered it cost-effective. People with COPD acknowledged their dependence on family and friends. They valued high-quality information and support and were critical where gaps were left. A

Table 2. Experiences of domiciliary NIV by theme and code.

	Healthcare professionals	Patients and carers
Clinical	<p><i>Addressing clinical indications</i></p> <p>'blood gases should show persistently elevated carbon dioxide, which may cause symptoms' (HCP5)</p> <p>'recurrent exacerbations' (HCP6)</p> <p>'you look at the literature, I don't think anybody knows who needs home NIV' (HCP4)</p> <p><i>Taking time to convey the purpose of NIV to patients</i></p> <p>'They also need some clear understanding of the role of NIV because it has got the name of a ventilator people think [it] is like an ITU life support machine' (HCP1)</p> <p>'patients with chronic illness do perhaps forget or they don't fully understand what they are being told ... needs to be reinforced' (HCP10)</p> <p>'it's not our decision, we can only advise ... ultimately it's their [patients'] decision and it has to be right for them ... you can't force patients to have this treatment' (HCP7)</p>	<p><i>Relying on their doctor's recommendation</i></p> <p>'I didn't want it on then but the doctor told me, he said "if you don't have that mask on, you will die, it's a life line" so I that was it, I kept it on, didn't I?' (P16)</p> <p><i>Wanting to extend their life</i></p> <p>'it will stretch my life out, I can live the daytime' (P18)</p> <p><i>Understanding the effect of the NIV</i></p> <p>'get air into my lungs and up my nose' (P7)</p> <p>'it's nothing you can feel ... it helps get rid of the carbon dioxide' (P11)</p> <p><i>Assessing the level of information and support given to them by clinicians</i></p> <p>'No they didn't give me enough information ... they didn't ... say this machine does this, this machine will do that, this will help you feel this way and I think they need to do that to make people feel more confident in having the machine' (P9)</p> <p><i>Acknowledging dependence on family</i></p> <p>'I can't do normal things ... husband ... helps me with the house work, he helps me with the cooking, helps me with the bath' (P8)</p> <p><i>Recognising the impact of their use of NIV on family</i></p> <p>'The problem was it [NIV] had a whistling noise, it kept the wife awake' (P14)</p> <p><i>Resisting financial limitations</i></p> <p>'I know they got to cut back, but I mean all I wanted was some Velcro [to fix the mask in place]' (P8)</p> <p><i>Experiencing discomfort and pain as a side effect</i></p> <p>'it's sore, it's as if someone has been rubbing your face all night, rawness like, tender' (P12)</p> <p>'that's the worse part of it, the dryness' (P11)</p> <p>'so loud, it's like an aeroplane revving up, it's vile' (P3)</p> <p><i>Adapting to the NIV equipment</i></p> <p>'At first it was a bit of a nightmare but I have got used to it now. It's just a way of life ... it's like brushing your teeth before going to bed ... I have to wear a plaster thing over my nose ... drink plenty of fluids ... put Nivea on my face and lips' (P10)</p>
Socio-economic	<p><i>Assessing the patient's level of social support</i></p> <p>'if they can't do stuff themselves and they don't have sufficient carers we can't really issue NIV' (HCP9)</p> <p>'[Secondary care providers] wouldn't know about the environmental or home factors because ... they don't do domiciliary visits ... that's where I think the support needs to come from the community' (HCP8)</p> <p><i>Balancing financial implications</i></p> <p>'cost savings far outweigh the cost of the machines in my opinion' (HCP4)</p>	
Technical	<p><i>Acknowledging side effects</i></p> <p>'nasal bridge side effects' (HCP6) 'skin reaction' (HCP10)</p> <p>'leak and blowing air into their eyes' (HCP9)</p> <p><i>Assessing physical capability</i></p> <p>'restriction in their upper limb mobility so they might find it very difficult to put the mask on themselves' (HCP3)</p> <p><i>Providing support for adaptation</i></p> <p>'there is good support nursing, district nurses, palliative care nurses, who go and encourage these patients to help them cope' (HCP5)</p>	

(Continued)

Table 2. (Continued)

	Healthcare professionals	Patients and carers
Experiential	<p><i>Acknowledging the importance of perceptions</i></p> <p>'definitely the psychological effect of the mask and how well it makes them feel whilst they are on it' (HCP8)</p> <p>'patients that go on NIV in the acute setting are quite traumatised by the experience, that you have to overcome' (HCP4)</p> <p><i>Achieving symptomatic relief and altering sleep</i></p> <p>'More awake and alert and capable of doing things during the day'. (HCP1)</p> <p>'I think a lot of it is the symptomatic improvement the patient gets, including quality of sleep and perceived reduction in dyspnoea'. (HCP6)</p> <p><i>Balancing extending life with quality of life</i></p> <p>'even if you can slightly offset that deterioration in quality of life, that is a very valid thing to do' (HCP3)</p> <p>'if someone is really terminal COPD are you really going to do them any good by sticking them on a machine which might make their quality of life worse' (HCP12)</p> <p><i>Experimenting with tolerance case-by-case</i></p> <p>'give it to them, see whether it benefits them. .. reassess them in 3 months' time ... re-do their investigations, bloods, spirometry ... see how much improvement and then ask them whether they feel improved' (HCP5)</p> <p><i>Acknowledging risk of dependence</i></p> <p>'it does make them feel so much better, and then you get an over reliance on it, so when they come off it they're feeling that they are getting short of breath, panic tends to set in ... feel they need to go back on it again' (HCP8)</p> <p><i>Evaluating patient's personality</i></p> <p>'it depends on the patient's personality as well, whether they will cope with it, intelligence as well ... more positive people ... willing to give things a try' (HCP11)</p>	<p><i>Reacting emotionally to using NIV</i></p> <p>'I felt like the man in the iron mask ... you are absolutely dying of thirst you can't have a cup of tea because it's so much trouble getting it off and putting it back and getting it right. Horrible to be honest, most uncomfortable, distressing you're tired, you're trying to get to sleep, your eyes are froze' (P20)</p> <p>'I love it ... I found the air refreshing, although there are some nights you find it a bit claustrophobic' (P9)</p> <p><i>Achieving symptomatic relief</i></p> <p>'it helps me breathe ... boosts me up ... more alert' (P8)</p> <p><i>Perceiving self</i></p> <p>'I look like Hannibal Lector' (P6)</p> <p>'it's become like normal to me to have it, so it hasn't put me out or hasn't made me think ... how beautiful are you' (P9)</p> <p><i>Relying on NIV</i></p> <p>'C3: It was only for night time first and then she [P3] had a bad turn and then they put it on her and psychologically ... she wanted it all the time She relies on it now. P3: To turn that off, a couple of minutes I'm gasping, literally gasping. I say please put it on, they say you've got your oxygen but I seem to depend on the machine as well'</p> <p><i>Staying positive</i></p> <p>'I think the worst thing anybody can do is start feeling sorry for themselves ... you have to fight all the way and pull yourself out you can't expect the doctors to do it all for you ... sometimes you think well I've got my [dog], I've got to keep something I love. My kids help me plant my garden ... You've got the illness you can't do things and accept that, but not the extreme that you don't try' (P9)</p>

NIV: non-invasive ventilation; HCP: healthcare professional; COPD: chronic obstructive pulmonary disease.

Table 3. Emerging themes to aid initiation and adaptation to domiciliary NIV in COPD.

	HCPs	Patients/carers
Clinical	Clarity regarding clinical effectiveness	Understanding physical effects and potential clinical benefit of NIV
	Use of multi-modal education – verbal, written and audio-visual	Balancing against risk of not having NIV
Socio-economic	Data on cost–effectiveness	Flexibility to reduce hospital visits by use of outreach or posting of equipment
	Involvement of community teams in NIV delivery and maintenance	Assistance with financial elements – such as how to claim electricity costs
Technical	Flexibility in changing masks	Guidance on skin protection
	Humidification	Guidance on ways to avoid dry mouth
	Easy access to support services	Help for their partners' sleep
Experiential	Teaching about NIV outside the acute setting	Cognitive-behavioural therapy to aid understanding of emotional reactions
	Honesty on limitations of NIV	

NIV: non-invasive ventilation; COPD: chronic obstructive pulmonary disease; HCP: healthcare professional.

few patients acknowledged financial restrictions, citing feelings of guilt when they had to ask for replacement masks, but resisted if perceived unfair.

Role of carers and the home environment. For HCPs assessing the patients' social situation was crucial; poor support led to concerns regarding NIV compliance and therefore subsequent efficacy. They assessed whether 'the home set up is appropriate for it [NIV]' [HCP #2] as those with 'very supportive family sometimes I think they have the best outcome' [HCP #5].

Adaptation to NIV was not an individual experience, but extended beyond to patient's families. Patients developed an increased reliance on their family for many aspects of their lives due to their disability, such as requiring assistance for routine self-care such as bathing or getting to hospital appointments. The patient's family also became the first port of call for any NIV-related problems, which patients saw as a burden; 'Poor husband has been up and down the hospital I don't know how many times ... I told him to go up and get another one and he got it and that wasn't right the poor bloke was traumatised' [Pt #3]. 'There was something wrong with my mask I can't remember what it was and my son had to take it in' [Pt #1]. Carers generally exhibited similar attitudes towards NIV as their partner/sibling; 'we just got used to it ... something you've got to put up with' [C #14] again accepting NIV because of the perceived idea that it is essential; 'she does really need it' [C #3].

There were no major differences observed in adaptation processes or patterns between patients with and without carers. Some patients who lived alone felt NIV impaired their ability to form intimate relationships 'You could never have a partner' [Pt #10]; this was acknowledged by one who commented on the way the NIV disturbed his wife's sleep (Table 2).

Technical

Patients and HCPs explained that NIV caused a number of problems. The mask was painful and caused facial sores. Dryness in the mouth and skin, noise and claustrophobia were also widely reported. However, patients described feeling that they had to adapt to discomfort, by way of numerous (often partial) technical fixes, such as using moisturiser or plasters on pressure points, alongside accepting discomfort because they 'had to'. This notion of forced adaptation to NIV links to the patients' view that they had no choice over whether to use it. HCPs' accounts emphasised ways in which patients could contact the service for support, rather than day-to-day coping mechanisms.

Experiential

This domain was recognised as vital by both HCPs and patients because it was a determinant of long-term NIV use. The perception of whether NIV was improving QOL, brought symptomatic relief and improved or disturbed sleep was important. There were two deviant cases; one patient exclaimed how he 'hates it' and that it should be given 'to people in prison, they won't go back again' [Pt #12], yet this patient still continues to use it. Another patient who had only used NIV at hospital declared that 'if the King came to me and said you gotta have one, I'd say no' [Pt #20].

Personality was cited by HCPs (ability to cope, acceptance), patients and carers (strength, a positive attitude to life) as an important determinant of success with NIV. Sufficient time to adapt to the treatment was noted to be important, but was highly variable – it ranged from 'a couple of minutes' [Pt #17] for some patients, up to 'months' [Pt #11] for others. The risk of patients becoming dependent,

clinically or emotionally, was acknowledged by all groups (Table 2).

Discussion

Our data demonstrate that starting and continuing domiciliary NIV requires active negotiation by patients and HCPs and is informed by clinical, socio-economic, technical and experiential forms of ‘evidence’. Improved understanding and a critical perspective on these could lead to more effectively targeted interventions to reduce any negative effects on QOL.

Clinical issues, including QOL and patient choice

The most important element for both patients and HCPs was whether domiciliary NIV was clinically effective, and what the risks were if not used. Individual clinicians may choose to weigh the clinical evidence up differently. In one large trial, 144 severe COPD patients were randomised to long-term oxygen therapy (LTOT) with or without NIV; patients on NIV were more likely to survive (hazard ratio (HR) 0.63 (0.40–0.99)); however, this was at the expense of QOL ($p=0.002$).¹² A more recent study has confirmed this survival benefit.⁴ Conversely, slight improvements in disease-specific QOL have been reported^{20,21} as have lower admission rates.^{5,21} Differences in outcome may have resulted from use of different tools to assess QOL – the 36-Item Short-Form Health survey (SF-36),¹² St Georges Respiratory Questionnaire (SGRQ)²⁰ and Mageri Foundation Respiratory Failure Questionnaire (MRF-28), respectively;²⁰ arguably the latter might be more informative in this highly selected population. Differing NIV protocols may also be relevant; higher pressures may result in more impressive changes in blood gases and lung function, alongside improved QOL.¹⁰ This implies that lack of clinical effect in some studies could simply be due to a suboptimal protocol.

Patients usually described symptomatic relief and improved daily function on NIV, outcomes not reported widely in previous domiciliary NIV trials. Primary outcomes in the largest two trials were severity of hypercapnia²¹ and survival,¹² demonstrating HCPs’ perception that use of domiciliary NIV should provide measurable clinical improvements rather than ‘softer’ symptomatic outcomes. Early work has now been carried out, albeit in a different population, to assess the feasibility of NIV for palliative care and has shown promise.²² This, together with our data, suggests that negativity regarding prior QOL data should be balanced against the potential for this treatment to improve lives.

Honesty about the potential risk and benefits of treatment was perceived as vital before prescribing domiciliary NIV. In most of the accounts, death and its potential

proximity were starkly absent, suggesting that discussions about palliative care were limited. Evidence across other chronic diseases suggests that patients value HCPs obtaining their opinion on end-of-life care, although many prefer clinicians to make the final decisions.²³ This applies particularly to older patients with poorer health or a lower socio-economic status,²⁴ as many of our group were.

Any medical ‘choice’ a patient makes is limited to the opportunities presented by HCPs unless they actively seek alternatives. Patient choice is an important value²⁵ cited by HCPs, but COPD patients’ accounts show that choices were highly constrained – indeed, many felt NIV was their only option to survive. To manage this lack of choice, patients explained that they trusted their doctors and were committed to extending their lives, even if that required adaptation to the physical and psychological side effects of NIV. This is an example of forced adaptation.

Socio-economic issues, including the role of carers

Health economics was a factor recognised by patients and HCPs; it may be cost-effective in those with recurrent hospital admissions.¹³ HCPs described situations where because of a perceived inability to cope, personality type or poor social support, they would not offer patients NIV, implying an inherent risk of inequality in terms of who is offered NIV. Despite this, it was apparent that many patients with no close social support received NIV in our study. Carer involvement has been found essential in patients using NIV for neuromuscular disease,²⁶ although differences in physical ability to put the machine could reduce the generalisability of this evidence to COPD. Where carers were present, they played a major role in NIV care delivery; however, this is an area in which external care might be provided, as acknowledged by interviewed HCPs (Table 2). Inequity might be avoided if greater systemic adaptations to domiciliary NIV were instituted (Table 3).

Technical issues and adaptive solutions

The necessity to ‘get used to’ NIV was a central theme. HCPs offered a range of solutions to improve tolerance: technical suggestions about the equipment, educational solutions to improve motivation and radical social changes, such as moving someone to a care home to improve carer support. Patient accounts stressed their acceptance of the need to adapt, even with substantial discomfort or anxiety. The latter may have implications for setting up of NIV, which is often done in hospital.²⁷

The process of adaptation appeared central for continued NIV use. An important tension was that whereas HCPs stressed access to support, patients often felt the burden of adaptation was theirs and did not discuss issues with their

HCPs. Simple measures like leaflets outlining technical solutions may be insufficient – these were often reported by HCPs but rarely remembered by patients. DVDs, video demonstrations posted online or patient-led workshops might be useful alternatives. Ongoing investment in machine or mask comfort will no doubt also help. Despite tolerance issues, our data concurred with previous studies in showing high levels of acceptance of domiciliary NIV by COPD patients.²⁸

Experiential issues

Perceptions of usefulness, especially in terms of improved ability to perform the activities of daily living and symptom relief, were important in decision-making, even where clinical explanations for these effects were unclear. These wider types of evidence may be key to managing end-stage COPD, where ‘cure’ is not achievable.

A number of patients reported bad experiences of acute NIV which influenced their opinion of domiciliary NIV and might be amenable to change. Education about NIV early in disease, so that it comes as less of a shock when admitted acutely, might help. Greater education of acute support staff could aid reassurance. Finally, the setting for starting domiciliary NIV might be changed – hospital commencement has strong support for technical aspects, but psycho-social support is poorer. Home commencement by community nurses could aid adaptation, particularly for fearful patients.

Strengths and limitations

The strength of this study was the range of perspectives collected, across HCP types and geographical areas (two hospitals). We reduced bias by obtaining lists of NIV patients from clinicians from which we purposively sampled eligible participants. However, the sample lacked ethnic diversity; this was reflective of those on NIV but was not reflective of the local population. While we continued recruiting until we felt that no new issues were emerging in the data, we were not able to return after analysis to further explore themes. It, therefore, remains possible that saturation was not achieved, and that the relative lack of number of carers could have biased findings pertinent to this subgroup. It is important to note that this study was not an efficacy study of domiciliary NIV and should not be interpreted as such.

Conclusion

Both patients and HCPs actively negotiate the process of patients’ adaptation to NIV, although their experiences and views are not always convergent. Their actions can be understood within the context of clinical, socio-economic, technical and experiential factors. While domiciliary NIV

is valued by COPD patients, the process of adaptation could be optimised by HCPs considering broader ways of explaining the process, other settings for initiation and generating more patient-centred data on its benefits.

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