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What can we learn from patients to improve their non-invasive ventilation experience? 'It was unpleasant; if I was offered it again, I would do what I was told'

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ABSTRACT

Objectives Non-invasive ventilation (NIV) is widely used as a lifesaving treatment in acute exacerbations of chronic obstructive pulmonary disease; however, little is known about the patients' experience of this treatment. This study was designed to investigate the experiences and perceptions of participants using NIV. The study interprets the participants' views and explores implications for clinical practice.

Methods Participants with respiratory failure requiring NIV were interviewed 2 weeks after discharge. A grounded theory methodology was used to order and sort the data. Theoretical sufficiency was achieved after 15 participants.

Results Four themes emerged from the data: levels of discomfort with NIV, cognitive experiences with NIV, NIV as a life saver and concern for others. NIV was uncomfortable for participants and affected their cognition; they still reported considering NIV as a viable option for future treatment. Participants described a high level of trust in healthcare professionals and delegated decision-making to them regarding ongoing care.

Conclusions This study provides insights into ways clinicians could improve the physical experience for patients with NIV. It also identifies a lack of recall and delegation of decision-making, highlighting the need for clinical leadership to advocate for patients.

INTRODUCTION

Non-invasive ventilation (NIV) is one of the few treatments shown to improve survival in chronic obstructive pulmonary disease (COPD) and is widely used in the management of acute exacerbations of chronic obstructive pulmonary disease

(AECOPD).¹ It has been estimated that in the UK alone NIV is used on 18 000 occasions per year.² With COPD destined to become the third leading cause of death and sixth leading cause of disability worldwide, the use of NIV is set to increase.³

While the data on the impact of NIV on survival in acute exacerbations of COPD is reasonable, little is known about the patient experience of this treatment.^{1,4} A call has been made for qualitative research on this subject to explore the patients' perspective of NIV treatment, which may allow health professionals to potentially improve the experience.⁵ Only four of the more than 20 randomised controlled trials of NIV in an acute exacerbation even comment on breathlessness as a treatment outcome, with conflicting results.⁶ Although two studies report on the approaches patients may use to adapt to NIV, no systematic exploration of the patient reality has been published.^{7,8}

This study was designed to explore the experiences and perceptions of patients using NIV in the context of respiratory failure secondary to AECOPD. The data set is part of a larger study exploring end-of-life issues in patients with COPD,⁹ and the purpose of this analysis was to focus on the patient's views of NIV treatment. The study interprets the findings and reflects on implications for healthcare professionals.

METHODS

The Canterbury District Health Board, the second largest in New Zealand,



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provides tertiary, secondary and primary services to a population of about 500 000. It is innovative in service delivery resulting in collaborative relationships between primary and secondary care.¹⁰

On the basis of international guidelines, NIV is offered by our service for patients with an AECOPD and acute respiratory acidosis. Strict local protocols guide NIV therapy, with one-to-one nursing at the initiation of treatment. The local mortality rate is ~20% with an intolerance rate of ~6%. The requirement for NIV served as a marker for advanced disease.⁵ COPD was confirmed with lung function testing for all participants. Exclusion criteria included active treatment for lung cancer, NIV requirement for an alternative diagnosis, non-English speaking, under 18 years or cognitive impairment.

Patients were approached prior to discharge from the Respiratory ward, once weaned from NIV and in a stable clinical state. An information sheet was given, and patients were informed that a research nurse would contact them about 2 weeks following discharge. Those who consented were interviewed in their own homes. The interviews were conducted by the same research nurse, and all interviews were audiotaped and transcribed.

Owing to the exploratory nature of this research, a qualitative approach was employed. Grounded theory methodology was used to explore patient experiences and allow theory to evolve during the research process. Grounded theory was also seen as appropriate because it allowed the researchers to bring theories based on their previous relevant research and clinical practice into this project, while continually developing this theory against the new data this project introduced. This methodology also goes beyond only reporting the patient voice/experience but is transparent in the role of how the researcher interprets this information and formulates theory of 'conceptual density.'¹¹

The research team developed a semistructured interview schedule. Questions were used exploring various areas of illness perceptions and quality of life. After the first interview was conducted, it became apparent that the experience of NIV was of particular significance and, in subsequent interviews, a specific open-ended question about the experience of NIV was included.

Data analysis

Inductive analysis was used to undertake two cycles of coding on the data by all authors (LB, AL, RW and SP). The first cycle used 'initial coding' which involved examining the data line by line and looking for similarities and differences. It also allowed for the researchers to reflect on the content of the data and its specific characteristics. Descriptive coding was then undertaken to further extrapolate the basic topic being described by the participant(s). The data were then reviewed and it was deemed necessary to enter a

second cycle of coding to further re-organise the data to develop theory. Therefore, 'theoretical coding' allowed for all categories and subcategories 'to become systematically linked with the central category'¹² which seemed to have the most relevance to the phenomenon being explored. To ensure the analysis was of high quality, each cycle of coding, definitions of codes and negotiated themes were reviewed by all four researchers. Analyses were undertaken using the software QSR NVivo v.10, a qualitative data analysis package which allowed for robust peer review of coding processes.

RESULTS

A total of 15 participants were recruited. During the analysis, it was identified that theoretical sufficiency was met and therefore no further participants were sought. All participants had severe or very severe COPD and presented in respiratory failure meeting the criteria for NIV. About two-thirds of the participants were women, living with their family and used long-term oxygen therapy (Table 1).

Through the analysis four themes emerged which highlighted key perceptions and experiences with NIV. These four themes were inclusive of levels of discomfort with NIV, cognitive experiences with NIV, NIV as a life saver and concern for others. These four themes will now be further described and presented within this section.

1. Levels of discomfort with NIV

Within this theme participants identified four specific areas of discomfort when having NIV as an intervention. This included their experiences with the mask, blood gases sampling, adjustment to airflow and synchronisation with NIV.

Table 1 Patient characteristics (N=15)

Demographics	N=15
Sex, male/female	9/6
Age (mean, SD, range)	69.2 (8.2, 55–89)
Domicillary status	
Living alone	1
Living with family	10
Residential care	4
Long-term oxygen therapy	9
BMI (mean (SD))	24.7 (6.2)
Severity of COPD	
FEV ₁ (L; mean (SD))	0.69 (0.33)
FEV ₁ % pred. (%; mean (SD))	26.4 (10)
PaO ₂ (mm Hg; mean (SD))	56.3 (10.9)
PaCO ₂ (mm Hg; mean (SD))	49.5 (9.2)
Ventilatory status on admission	
Arterial blood pH (mean (SD))	7.28 (0.06)
PaCO ₂ (mm Hg; mean (SD))	73.4 (0.06)
PaO ₂ (mm Hg; mean (SD))	53.9 (15.7)

Mask

Participants reported that they disliked their experience with the mask. They noted that it was often too tight and made them claustrophobic with feelings of suffocation and loss of control, which made it difficult for them to relax. This led participants to report a negative NIV experience.

P9: it was hideous! I have felt a little bit like the man in the iron mask, because your head feels encased.

P14: That was terrible, I tore it off! I felt I had been suffocated

Blood gas sampling

Participants associated blood gas sampling as part of NIV. They recalled this as painful and something they dreaded. It was often the most difficult procedure for them to navigate in the NIV process.

P8: Had lots of blood gas tests, it depends who take them. Some people are alright, and other people make hurt like hell!

Airflow

Participants commented that the sensation of air being blown at them made it difficult for them to breathe. This induced a sensation of fear and feeling of wanting to push the mask away. Other participants described a better experience when the NIV was started at lower pressures and was gradually titrated upwards.

P13: When I was in the wards this time, it wasn't as bad because they don't turn save the oxygen up so high, once they get it on you, they increase it then.

Synchronisation with NIV

Participants described how they learnt to synchronise their breathing with the NIV, which made the experience more bearable. They reported that it was difficult to maintain the synchronisation over a long period of time.

P6: You have to adjust to it. You want to take a breath, but the machine decides it's another time you want to take a breath. It's a bit hard sometimes.

2. Cognitive experiences with NIV

Some participants reported that specific details of the initiation of NIV were often difficult to recall due to cognitive experiences that impaired their recollection of events. This included the inability to recall specific events and the presence of hallucinations.

Recall of events

Participants described a loss of memory about the admission to hospital and initiation of NIV. The actual NIV experiences were difficult to recollect and there was general confusion of events during the acute presentation. Participants remembered feelings of

impending death, recalled admission to ICU but struggled to recall the details of initiation of NIV.

P10: I basically only knew about it afterwards, after two days, I remember coming to, with this mask on my face, and it has to breathe for you, do everything for you.

P13: I was in the ICU and I are just about died on the way to hospital. I might have stopped breathing in the ambulance, I can remember getting into the ambulance but then don't remember anything else.

Hallucinations

For some participants the presence of hallucinations during their admission was part of their experience of NIV. This included hearing voices and recalling experiences of multiple activities occurring within the treatment room.

P10: I was quite happy, going where I was going (i.e. dying), but I heard noises and it was in my head. I was seeing things happening around the room, other things were going on, and I was conscious of other things happening at the other beds. I heard things that were happening across the way, I was taking it all in.

3. NIV as a Life saver

Participants shared many stories of NIV as a 'life saver'. Within this theme, two subthemes emerged that captured the participant narrative of what was meant by 'life saver'. This included describing NIV as a safety mechanism and providing rationalisation about the mask, adaptation and delegated decision-making in their recovery.

Safety mechanism

Some participants described that access to NIV was crucial for their survival, and expressed a trust in NIV to keep them alive. These participants remarked that NIV could keep them breathing when it was beyond their own capacity to do so. In the future, they would choose to have NIV when recommended by doctors to stay alive. In these descriptions, NIV was portrayed as a safety mechanism for survival.

P4: I really got to trust it in my last visit to hospital.

Rationalisation

Participants remarked that although NIV was a 'life saver', specific strategies were needed to overcome difficulties with NIV. This involved cognitive and behavioural adaptations to make NIV 'bearable'. Participants provided a discourse of adaptations and rationalisations that they used to continue NIV treatment despite its unpleasantness.

Adaptation to the mask

Participants self-initiated specific strategies to tolerate the mask. This included externalising their feelings of being uncomfortable, reflecting on others having

worse experiences and labelling the mask as a 'life saver'. It was just something they had to bear to survive. In contrast, one participant felt that NIV would have killed them as they perceived that the mask had actually stopped them from breathing properly.

P12: It's not pleasant but it's okay, I understand some people panic under it, if it is clamped down tightly on you, I didn't find that a problem.

P15: Well, the first time I woke up in the middle of the night and it actually stopped me from breathing, I yanked it off and felt that I had saved my life by doing so.

Psychological adaptations

Participants gave examples of adapting their thoughts and behaviours in order to tolerate NIV treatment. This included accepting that pain was part of the process, finding inner resilience, coping with inconveniences and focussing on specific activities/people they wanted to engage with in the future. This was driven by a desire to survive their acute illness.

P1: My focus is really getting back to the rest home. I have to get back to tease Ray about his dislike of pumpkin soup.

P12: It was breathing for me and doing the job it had to, and any inconvenience you have to put up with because it is in your interests.

Decision-making about future treatment

Most participants gave an account of how they did not believe it was their decision to determine what interventions they should have in their future care. They saw this to be the role of health professional' decision. They expressed trust in a 'more experienced, qualified person to make that call' and felt comfortable to delegate that decision.

However, one participant reported that a non-resuscitation order was in place, and felt strongly that the NIV intervention had breached this request. Another participant expressed that they had 'a pretty good innings' and did not specify whether they would want NIV treatment in the future.

P11: It was unpleasant, if I was offered it again, I would do what I was told. You do what you are told when you are in that situation, you expect them to make you better, so you do as you are told. I just take what they give me.

P10: Knowing what I know now, I would just as soon as not do that. It all came about because of them having the BiPAP machine. I had gone to a lot of trouble to organise a non-resuscitation order through the Dr, my family, St John's.

4. Participant concern for others

Participants observed that their decision regarding NIV treatment had, had an impact on their lives, as

well as those around them. Participants noted specific concerns for their families and the health professionals that supported them.

Concern for family

Some participants remarked that repeated admissions and uncertainty about outcome was exceptionally tough on the family. Participants felt a level of guilt and grief about the experiences of the family. They reported internal conflicts about wanting to live as part of the family yet not wanting to survive to remove the burden of care from loved ones.

P6-Three years ago I actually stopped breathing. I don't remember anything about it, it was tough on the family.

Concern for health professionals

Participants were mindful of how their illness and behaviours impacted on health professionals. This included portraying that they were comfortable with NIV, even when they were not. Participants commented on feeling embarrassed about their behaviours such as panic and distress. One participant reported feeling ashamed as, during the initiation of NIV, she verbally abused nursing staff. However participants were grateful when health professionals continued to provide support and care.

P14: and I admit I was ashamed of myself because I abused the nursing staff.

P14: I felt sorry for the nurse I had abused, but she still kept holding my hand.

DISCUSSION

This study sampled a representative cohort of patients with severe COPD, who underwent NIV and explored their experience and perceptions. The inductive analysis and descriptive coding allowed us to identify participant themes. After data saturation, four main themes emerged: levels of discomfort with NIV; cognitive experiences with NIV; NIV as a life saver and concern for others. The discomfort with the mask itself and blood gas sampling was not surprising and needs to be taken into consideration when offering NIV treatment. A strong theme was the impaired recall and memory lapses while receiving NIV. It was interesting to see the rationalisation that participants used to navigate the NIV experience. Also of note was the high level of trust placed in healthcare professionals, particularly around decision-making.

NIV in patients presenting with respiratory failure during an acute exacerbation of COPD is one of the few interventions which has shown to improve survival. The participants describe various unpleasant aspects of the treatment such as the tight-fitting mask, the feeling of claustrophobia and suffocation. In addition, several participants recalled blood gas sampling

as worse than the BiPAP mask. Others comment on the effect of high airflow, probably due to air leak, and difficulties synchronising with the NIV machine.¹³ When discussing the treatment options with patients and their families, the healthcare team needs to be mindful of the considerable discomfort experienced during this treatment. Healthcare teams may wish to consider mitigating some of these adverse experiences by adjusting titration protocols, providing guidance around mask fitting and offering anxiolytics.

A significant finding is the severely impaired recall participants describe following treatment with NIV. Matthews⁸ described widespread hallucinations in patients using NIV. Although few of our participants reported hallucinations, most reported a lack of recall. The prominent feature was the distortion of their memory of the entire experience. This has implications for care during the administration of BiPAP during an acute episode. The patient's distorted view of events prevents them from understanding the life-threatening nature of the episode. This leads to the inability for them to plan for the future using this experience, which has also been identified by Seamark *et al.*¹⁴ Patients are very vulnerable during this episode and rely heavily on guidance by health professionals. For future planning, it is the responsibility of the clinician to elaborate on the seriousness of the episode of respiratory failure.

Participants described cognitive and behavioural adaptations in adjusting to the BiPAP machine, in which they drew on internal strategies such as rationalisation, re-prioritising and future planning to negotiate the period of the BiPAP treatment. Participants also used external networks to build resilience to tolerate the experience. This complex and often chaotic narrative decision-making process¹⁵ is in stark contrast to the combined decision-making often negotiated with patients in treatment for lung cancer. This results in patients with COPD delegating a greater proportion of their autonomy and decision-making to the healthcare professionals.¹³ Therefore, the clinician needs to take leadership in making decisions about the appropriateness of BiPAP treatment, taking into account any previously expressed views of the patient.

Our study explored strictly the participants' experiences after an episode of NIV. We did not assess cognitive function formally, neither can we infer the lack of recall is related to hypoxia hypercapnia, the medications received or yet another mechanism. In addition, these findings may not be easily generalisable as they may be specific to our healthcare setting.

In summary, we have reported on a representative cohort of patients with severe COPD after an episode of treatment with NIV for acute respiratory failure. Theoretical sufficiency was reached within the analysis with four themes emerging from the data. It is important that clinicians are aware of the discomfort of NIV, the change in recall of their NIV experience

and the need to take leadership in clinical decision-making for patients in chronic respiratory failure.

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Contributors Initial research design and interview questionnaire was carried out by AL. AL, LB, SP and RW were involved in the data analysis and writing of the article. All the authors have read and approved the final version of the paper.

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