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The use of non-invasive ventilation at end of life in patients with motor neurone disease: a qualitative exploration of family carer and health professional experiences

ABSTRACT

Background

Non-invasive ventilation (NIV) improves quality and quantity of life in patients with motor neurone disease (MND) who have respiratory failure. Use of NIV may however result in complex clinical issues for end of life care, with concerns as to whether and how it should be withdrawn.

Aim

The study aimed to describe carer and health professional experiences of end of life care for MND patients using NIV.

Design/participants

This paper reports data from qualitative interviews with family carers and professionals following the death of patients with MND who were using NIV in the final phase of the disease.

Results

Ten of the 20 patients initiated on NIV were using it in the end of life phase of their disease, with five using it for 24 hours per day. Interviews were carried out with nine family carers and 15 professionals. Nine recurring themes were identified in the data. Both carers and healthcare professionals perceived that the terminal phase of MND was unexpectedly rapid, and that this often led to unplanned interactions with the emergency services. Carers of patients who used NIV, perceived NIV as aiding patient comfort and anxiety at the end of life.

Conclusions

The use of NIV was described as beneficial and was not perceived by carers or most professionals to have adversely impacted patient end of life experience. The study highlights variation in patient wishes regarding usage towards the end of life, uncertainty regarding appropriate management amongst professionals and the importance of disseminating end of life wishes.

Key words

Motor neuron disease, amyotrophic lateral sclerosis, noninvasive ventilation, end of life care, qualitative research

INTRODUCTION

Motor neurone disease (MND) is one of the most common neurodegenerative conditions of adult life with an estimated annual incidence of 2 in 100,000 and prevalence of 5-7 per 100,000 in most countries.[1 2] There are three recognised patterns in MND – limb, bulbar and respiratory onset of which limb-onset is the most frequent.[3] Life expectancy from diagnosis varies, but is typically between three and five years.[4] The care approach is largely palliative from the point of diagnosis and includes symptomatic management, nutritional and psychological support, assistive devices and respiratory support.[5] Non-invasive ventilation (NIV) respiratory support systems deliver variable inspiratory and expiratory pressures via a mask interface triggered by spontaneous effort. NIV is typically used overnight by MND patients initially, with additional daytime use in the later stages of the disease.[3]

NIV is recommended to prolong survival, preserve respiratory function and improve or maintain quality of life (QoL) in MND patients.[2 4 6] There have been concerns however that use of NIV leads to "difficult decisions in difficult circumstances" regarding if and when this intervention should be withdrawn.[7] Rapid rather than gradual withdrawal, medical input in the withdrawal process, and discussion and forward planning with patients, family and the multidisciplinary professional team is recommended.[8 9 10] Caregivers however report a lack of information on the course of the terminal phase, and the provision of services for MND patients is known to differ from unit to unit with varying collaboration between agencies.[9 11 12 13]

The purpose of the present study was to investigate the experiences of family carers and health care professionals who were involved in caring for patients with MND using NIV. We aimed to explore attitudes and perceptions regarding use of NIV at the end of life.

METHODS

Design

The data reported here are from a qualitative longitudinal study which carried out in-depth interviews with MND patients who had been recommended to use NIV and their family carers over the course of the disease. This paper focuses on interviews with carers that were carried out one month following the death of the patient, and interviews with health care professionals (HCPs) who were nominated by these carers as having been closely involved in the final months of the disease course of the MND patient.

Data collection

The local research ethics committee approved the study prior to initiation. Participants were recruited from the neurology clinics at Sheffield Teaching Hospitals, by the consultant neurologists (CJM and PJS) at the time a need for NIV was identified. The inclusion criteria were: a diagnosis of MND; type 2 respiratory failure; and capacity to give informed consent. There were no exclusion criteria and patients and their carer were recruited consecutively. In accordance with standard practice in qualitative studies sampling continued until saturation of data was reached and no new concepts emerged.[14] Data were collected between May 2010 and April 2012 from time of first attempt at initiation on NIV to death of the patient, when the interviews reported here were carried out. The semi-structured interviews were carried out either in carers' homes or the health care professional's (HCP's) place of work and lasted 45-60 minutes based around a pre-defined interview schedule (Appendix 1). The interviews were carried out by SB and ST (female research fellows with substantial previous experience of qualitative interviewing) and were audio-recorded and transcribed verbatim.

Data analysis

Techniques of thematic analysis were used with systematic coding and retrieval of the data supported by NVivo8 software.[14 15] Coding of the data was led by SB, with themes developed by line-by-line reading of transcripts. Data within each theme were checked for consistency via text searching, and constant comparison methods.[16] Particular attention was paid to identifying negative instances (differing views) in the data. Following initial coding, the anonymised data and the coding tree were shared and discussed at several research team meetings to establish consensus.

RESULTS

Of the 20 patients who had been recruited to the study, five were surviving at the two year end point, four patients had discontinued NIV usage and one had withdrawn from the study. This paper therefore reports data from the ten patients using the system who were followed to the end stage (one of these had no carer). Nine family carers and 15 health professionals were interviewed following death of the patient (see Tables 1a and 1b for characteristics of the participants). All but one of the HCPs who had been nominated by carers agreed to participate, with the sample encompassing seven different professional groups. Analysis of the interviews with these 24 participants (relating to ten NIV users) identified nine recurring themes regarding views and experiences of using NIV at end of life (Box 1).

Box 1. Key themes in the data

1. Unexpected speed of deterioration
2. Hospitalisation versus dying at home
3. Attempts to resuscitate
4. Decision-making regarding the withdrawal of NIV
5. Peaceful final moments
6. Turning off the machine
7. Professional uncertainty regarding the use of NIV
8. Positive impacts of NIV use
9. Concerns regarding NIV use

1. *Unexpected speed of deterioration*

End of life for patients in the study was often described as being unexpectedly rapid by professionals, and this adversely impacted on the plan in place for end of life care, for example:

> “It felt like a more sudden and dramatic end than I had imagined. I had imagined being able to guide the family through it in a bit more of a controlled way than when it eventually happened” (HCP1).

Four carers also described surprise at the speed of decline with two expressing regret that they had not recognised signs of deterioration, for example:

> “I just didn’t see it coming…... I felt so stupid, [be]cause the signs were there…… I should have seen them” (Carer6).

While the rapidity of the final phase reportedly created issues, it was also described as a positive element by two carers and two professionals in terms of being easier for families:

> “For this patient it worked extremely well that his deterioration was a period of only less than twelve hours” (HCP6).
>
> “I didn’t realise how quickly he would go down, I really didn’t. But I'm thankful that he did” (Carer9).

2. Hospitalisation versus dying at home

All patients reportedly had wished to die at home, however two had spent their final days in hospital and a further patient had been admitted in the end phase resulting in substantial efforts to get him home prior to death. One carer in addition described how her spouse had refused his doctor’s recommendation to go to accident and emergency a week prior to his death in case he was admitted:

> “He didn’t want to go to hospital....he wouldn’t go, he didn’t want to go. I think what was on his mind was he didn’t want to die in the hospital…. he wanted to die with us, with his family, that’s what was on his mind, I think” (Carer9).
>
> Obviously he was dying and he wanted to die at home and the family were getting a bit exasperated that things weren’t moving, and I managed to get the equipment set up to get him home that day” (HCP15).

Professionals reported that issues of timing could be responsible for the wish to die at home not being achieved. Participants described how discussion of advanced care plans required careful timing to ensure that it was carried out early enough, and staff with knowledge of the care plan needed to be available at key times of rapid deterioration:

> “Unfortunate timing really, like (I) say had he not taken ill until a week later I think some of that paperwork would have been in place and he may not have gone into hospital” (HCP15).
>
> “Unfortunately it was over a bank holiday period and they didn’t get the immediate care (at home) when they asked for it so she was admitted” (HCP9).

The patients who had been admitted to hospital had arrived via emergency calls to the ambulance service (made by carers in two cases and staff in one instance):

> “He just couldn’t breathe, you know, without it on. So that’s when I sent for the paramedics” (Carer8).

Professionals highlighted the difficulty for both carers and HCPs in making the decision whether or not to telephone for an ambulance, and for ambulance staff to have a full understanding of the situation:

> “The first thing that people do is to ring the ambulance. It takes a lot of strength and courage to decide this is that time and I’m not going to ring the ambulance. Very often it’s the first….. ‘It’s not time yet’. ‘There’ll be another time after I’ll ring the ambulance this time” (HCP14).

> “The rapid response team were unsure and didn’t really know what was going on, got the ambulance, so she was admitted” (HCP9).

3. Attempts to resuscitate

Participants reported that two of the patients had been subjected to attempts to resuscitate which had been highly distressing for the families. For one further patient attempts to resuscitate were about to be made and had been halted following a phone call from one of the HCP participants to the hospital team:

> “Anyway this paramedic comes in and he was going to try and resuscitate him. I said you’re too late he’s gone. Anyway he put it on and of course he was flat, you know flat. Next thing the police came and they were here for over two hours questioning us” (Carer4).

> “There were resuscitation attempts which I think must have been very hard for the family and for medical staff actually” (HCP1).

While advance directives had been put in place for some patients, staff described the challenge of broaching the subject of end of life with other patients who were resistant to raising the topic:

> “Most people want to try and maintain an optimistic view that there’s going to be a cure for this disease before it gets them, and certainly I can think of a few people at the minute, so I suspect that will be the case, you know that they maintain this going to be positive, can't discuss it’” (HCP15).

Optimal timing of the discussion in a rapidly progressing disease could be an issue. One participant described the initiation of NIV as providing a useful opportunity to raise the subject of patient wishes:

> “I think NIV is an opportunity to discuss and probe people, ask people what do they want to know, what do they sort of know about the future, and what treatment do they want” (HCP4).

4. Decision-making regarding withdrawal of NIV

Five patients had NIV in 24 hour operation at the point of death. One regular night time user discontinued during the final month simply by stopping using the system. This was reported as being due to finding the fitting and removal of the mask too onerous, as physical functioning declined. Another regular night time user passed away during the daytime, and three low users (less than four hours per night/day) also did not have the system operating at the time of death. Any potentially difficult decisions regarding whether and how the system should be discontinued at end of life therefore seemed not to have arisen for these NIV users.

Participants recalled discussion with the patients who had the system in 24 hour use regarding whether they wished to continue. These patients had reportedly made the clear decision that they wished to keep the keep the system in place:

> “I said to (the patient) you don’t have to fight any more for husband and if you are tired and you want to say enough is enough, that’s ok. And if you wanted to take the mask off to make things easier you can do. I said do you want the mask to come off and she shook her head (HCP5).
>
> “We did discuss it at various points during his illness and whether he felt at any stage as to whether he might have had enough and want to get rid of it and he was very strongly of the opinion that he wanted to keep it going as long as possible” (HCP1).

5. Peaceful final moments

Descriptions of the final days and hours of patients who died with the mask in situ appeared little different from those who did not. Descriptions tended to be of a peaceful end, with no reports of choking or struggling for breath in the final moments:

> “It just looked like he was asleep”. (Carer of 24 hour user).
>
> “You could tell his breathing had changed and then she said oh he's gone”. (Carer of 24 hour user).
>
> “I glanced across and I could tell he’d stopped breathing. It was as peaceful as that. Just as though he’d gone to sleep”. (Carer of patient not using NIV at time of death).

6. Turning off the machine

A potential issue for NIV users that was mentioned by three HCPs and two carers concerned the machine continuing to operate after the patient was deceased:

> “Yeah, and all of a sudden he went and he had got the machine on and with it making a noise we weren’t sure” (Carer4).
>
> “One of the difficulties afterwards was - is he still breathing, because the machine was breathing for him and then she used her judgement to make the decision to turn the machine off because that would be a very distressing situation where the machine was breathing for somebody who had passed away” (HCP6).

One carer seemed to perceive that the machine working might prevent respiratory failure:

> “He had his full face mask on so we didn’t expect anything to happen really” (Carer1).

Two staff highlighted the importance of families having a clear understanding of the way that the machine functioned at the end of life phase to overcome this concern:

> “They clearly didn’t have such a good understanding of the fact that when someone dies the machine doesn’t work...not that it is the other way round” (HCP1).

> I always say to people the machine is not breathing for you, you're breathing, you're just triggering it" (HCP2).

7. Professional uncertainty regarding use of NIV

Carers were asked to identify professionals most closely involved in care of the patient in the final phase. For the majority, medical professionals seemed to have had only limited involvement, with decisions regarding NIV at the end of life being predominantly made by professionals from community teams. These participants described some uncertainty regarding how best to manage NIV in the final stage and whether usage should be withdrawn:

> "And I think because people become obviously quite dependent on it there's also a bit of panic about…. well, if they don't use it they fear what the end will be like, and do they need to keep using it...I suppose it's lack of education isn't it" (HCP3).
>
> "The only gap, like I've said before, I'm not quite sure about the mask taking off and what would happen with it" (HCP13).

The strategy of weaning down usage was reportedly being considered for two patients and was recalled as having being used for patients outside the study:

> "The plan had been to increase that (Midazolam) to a point where she wasn't aware and then wean her down" (HCP4).
>
> "It is a natural thing to just turn the machine down" (HCP2).

The uncertainty regarding when to withdraw NIV seemed partly influenced by the perception that NIV was being used as a ventilator, rather than as providing support:

> "Where they've said we want to take the mask off, and I've found that very awkward because I've felt that they've been using it as… like a ventilator, like turning the machine off"(HCP13).
>
> "But withdrawing it I think also for people, feels like killing the person, I think that's often the perception" (HCP15).

8. Positive impacts of NIV use

Carers were asked whether in hindsight they believed that using NIV had been a positive experience in the final months. Carers of regular users outlined positive impacts in terms of extending life and supporting breathing:

> "I think it was. I think it definitely prolonged his life.... it was just something you accept because without it he couldn't breathe, definitely, it is something that helped" (Carer1).
>
> "As soon as he took it off he couldn't breathe at all and he wanted it straight back on. He needed it…… he wouldn't have survived a quarter of the time without it" (Carer6)

Carers of low users and those who had discontinued usage described how patients had perceived only limited benefits from the system, or had found the physical limitations as the disease progressed to be an obstacle to use:

> "He wasn't totally convinced that it was making a difference but he still persisted with it when he felt, yeah, I ought to". (Carer7)
>
> "So by the time he'd got it off and everything, you know, he just felt tired, whether it was worth the hassle, you know, because he didn't feel like it was making him, you know, any better. (Carer9)

Positive HCP perceptions were described in terms of the system providing comfort and reassurance:

> "I think it's a bit like the oxygen that we get prescribed for our palliative patients but it is the comfort to them more than anything" (HCP4).
>
> "It does give people a lot of comfort and a lot of reassurance, not only for the patient but for the relative as well. That they feel they're actually doing... you know, when the patient's in distress they feel they can put that on and they can relax a little bit more with it and breathe a bit better with it" (HCP9).

9. Concerns regarding NIV use

While the majority of participants described positive experiences of NIV usage at the end of life, three professionals mentioned some concerns. Two HCPs recalled that the mask could muffle patient attempts to communicate:

> "Sometimes the noise of the mask masked what she was trying to say" (HCP4).

One of these HCPs also raised the issue that patient dependence on the mask being in place obstructed the provision of mouth care in the final phase:

> "She got so distressed without the mask support that her mouth was in a terrible state. You couldn't get in to give her proper mouth care because it meant taking the mask off for periods of time" (HCP4).

DISCUSSION AND CONCLUSIONS

Death for these patients using NIV was peaceful, with the possible exception of two for whom resuscitation had been attempted (which seemed unrelated to the presence of NIV). This work is consistent with the existing literature in that death is usually peaceful in MND and demonstrates that use of NIV at end of life need not change this. Choking to death is often described as a concern however in our sample (in common with in other reports) this was not the reality.[17 18] The use of NIV was not perceived to have had an adverse impact on the end of life phase, and was described as being used to comfort and ease anxiety. Carers of regular users echoed previous research findings that NIV prolongs life whilst maintaining the quality of life of patients.[3] Carers of these participants viewed this as a positive outcome.

The study highlights that in spite of careful planning, patients can end their lives in acute emergency hospital facilities due to carers or clinical staff calling emergency services in the final phase. This confirms the importance of disseminating the end of life wishes regarding withdrawal or continued usage of NIV, and any advance directives to avoid distressing and inappropriate resuscitation attempts. The rapid deterioration in the final phase was described as coming as a surprise to many professionals. Initiation on NIV should be seen as presenting an opportunity for difficult end of life decisions to be broached.[7] NICE guidelines also suggest that discussion of end of life decisions should be ongoing throughout NIV use.[10]

The study found that the practice of “weaning off” NIV was described by some professionals, although guidelines recommend removal/discontinuation rather than altering settings.[9] Professionals typically reported uncertainty regarding managing NIV in the final phase, suggesting the need for further dissemination of information. As community staff who may have little previous experience of the final phase of MND and NIV often deliver terminal care (as patients are unable to travel to secondary care centres at this phase of the illness) dissemination of patient wishes to these groups are imperative. Other studies have similarly reported limited involvement of medical staff, including general practitioners in end of life care.[19 20] Some HCPs in the current study described how the end stage in MND differed from their experiences with palliative care for other patients groups such as those with terminal cancer. This highlights the need for further support and information for these professionals.

The data we have collected represent the perceptions of a relatively small sample of family carers and HCPs in one region of the UK and are weighted towards males and patients with limb-onset MND. Previous work has suggested that end of life can be different for patients with bulbar symptoms.[19] It may be of note that the two bulbar-onset patients in this study were not using NIV at time of death. This paper also reports perceptions of NIV for successful users rather than those who had made the decision not to use NIV, or those who discontinued shortly after initiation.

The study underlines the individual variation in patient use of NIV over the course of the disease and echoes previous work which reported that half the users of respiratory support systems discontinued them before death.[21] In the current work lower users of NIV were less likely to die with the system in operation, and discontinuation seemed to be associated with patients perceiving less benefit. For these patients it seemed that there was no need for discussion and decision-making regarding withdrawal. All but one of the patients who were regular users tended to progress to 24 hour usage in the final phase, stimulating discussion of end of life use by professionals. These patients were reported to have perceived benefits even in the final phase and made a clear decision to continue. These data provide evidence-based information which may support this discussion of patient choice regarding whether to continue NIV usage in the final stage of the disease.

Conclusions

The study suggests that use of NIV does not have a detrimental impact on end of life for patients with MND and was reported to be beneficial by many participants. The study highlights variation in wishes regarding usage amongst patients towards the final phase, and the need to ensure that carers are fully aware of how the system functions. We found uncertainty regarding management amongst many health care professionals and reported occasions when MND patients were taken to emergency hospital facilities at the end of life together with instances when resuscitation was attempted. The results of this study confirm the importance of disseminating end of life wishes and advance directives.

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Conflict of interest statement

The authors declare that there is no conflict of interest.

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Appendix 1. Interview topic guides

a) Carer final interview topic guide

1. Introduction – purpose of interview, outline project aims.
2. How was the last month? What kept you going?
3. Effects of NIV on patient's day-to-day activity - sleeping, communication, feeding washing/showering/dressing/shaving, concentration, fatigue levels, coughing/choking, getting out and about (if relevant)/isolation from outside world, independence.
4. Effects of NIV on carer's day-to-day activity (probe isolation/loss of freedom/fatigue).
5. Using the equipment - mask/user interface, using the machine, mouth care (dryness, extra secretions, anything else).
6. Support – how much needed over last month, source of support (primary/secondary care), success in getting support, how often was it needed?
7. Obstacles – any way things could have been better managed? Anything which might have made a difference?
8. Benefits of NIV use (probe dependency)
9. Problems/unexpected difficulties?
10. How did partner cope with the NIV?
11. With hindsight – what was the effect of using the NIV - on patient, on carer.
12. Did you have any way of planning what the patient wanted to happen when their MND reached a more advanced stage. Probe any advance directive, probe use of NIV at time of death.
13. Any formal palliative care support? How did this happen? Was this right for you?
14. With hindsight was the NIV a good idea? What advice would you give to someone in a similar situation? Probe balance between quality of life and prolongation of life.
15. Do you have any message for the hospital about the service / NIV support?
16. Anything else you think we should talk about?

b) Health professional interview topic guide

1. Introduction: project aims, aims of interview, confidentiality.
2. Involvement in care of patient – general role, pattern of contact.
3. Focus on NIV for this patient – benefits, disadvantages / drawbacks, specific issues.
4. What worked well - for patient, for carer, for you?
5. What didn't work well?
6. With hindsight, what do you think of the use of NIV for this patient?
7. With hindsight is there anything which could/should have been done differently?
8. Professional prior experience of NIV.
9. Personal impressions of NIV.
10. Any particular challenges using NIV for patients, carers, health professionals.
11. Access to information (source, ease of access, satisfaction with information).
12. Ease of familiarisation with the system.
13. End-of-life care issues – how do you manage end-of-life care with NIV (probe decision-making regarding turning machine off).
14. Anything else you think it is important that we talk about?