

Non-invasive ventilation for people with neuromuscular disorders in Australia and New Zealand: a qualitative study of clinician perspectives

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The known: Non-invasive ventilation is critical for treating chronic respiratory failure in people with neuromuscular disorders.

The new: Two major themes were identified in focus group and interview sessions with clinicians who provide non-invasive ventilation services for people with neuromuscular disorders: decision making for current practice and resource constraints. Factors at the system, organisational, and health professional levels influence the provision of quality care; current practice may both place lives at risk and be unsustainable.

The implications: Equitable non-invasive ventilation service delivery in Australia and New Zealand requires local guidelines, specific financial support for respiratory care for people with neuromuscular disorders, and further training for clinicians.

The prevalence of neuromuscular disorders in Australia and New Zealand is estimated to lie between 23 and 160 per 100 000 population.^{1,2} Progressive weakening of the respiratory muscles responsible for inspiration, coughing, and maintaining upper airway clearance can lead to chronic respiratory failure,³ reducing quality of life and accounting for 80% of the morbidity and mortality associated with some neuromuscular disorders.^{4,5}

Home-based, non-invasive ventilation is important for many people with neuromuscular disorders and chronic respiratory failure.^{6,7} Night-time use is initially typical, but dependency may increase (more than fifteen hours a day).^{7,8} Use of home-based non-invasive ventilation for people with neuromuscular disorders has increased over the last seven years in New Zealand,⁸ to 4.8 per 100 000 population in 2022.⁹

Successful non-invasive ventilation depends on the early identification of clinical need, national and local health infrastructure for supporting and monitoring therapy, appropriately trained staff who can determine optimal ventilator settings, and affordable or subsidised treatment costs.^{8,10-12} Domestic and overseas non-invasive ventilation guidelines are used inconsistently across Australia and New Zealand, especially for people with neuromuscular disorders.^{8,9} Some clinicians use the New South Wales guidelines¹³ (the only published Australian guideline) while others have reported using a range of overseas guidelines, with different outcomes.^{14,15}

All these factors can affect quality of care, leading to differences in health outcomes for people with neuromuscular disorders.^{8,15,16} As little has been published in this area, we explored the experiences of Australian and New Zealand clinicians with respect to care pathways, their awareness and use of non-invasive ventilation guidelines, and their perspectives on

Abstract

Objectives: To explore the experiences of Australian and New Zealand clinicians with respect to care pathways, their awareness and use of non-invasive ventilation guidelines, and their perspectives on delivering quality non-invasive ventilation services to people with neuromuscular disorders.

Design, setting, participants: Qualitative study; semi-structured focus groups and individual interviews with Australian and New Zealand clinicians who provide non-invasive ventilation services to people with neuromuscular disorders, recruited from participants at a 2017 sleep medicine conference. Interviews were conducted during 1 October 2017 – 31 May 2018.

Main outcome measures: Major themes identified by an iterative, semantic, and inductive analysis.

Results: A total of 28 participants attended the four focus group sessions and five individual interviews; fourteen each from New Zealand and Australia, seventeen women and eleven men, eighteen physicians and ten other clinicians. Two major themes were identified: decision making for current practice, and resource constraints. Participants noted variable use of clinical guidelines and limited training to meet the needs of people with neuromuscular disorders who require non-invasive ventilation. They described a lack of dedicated funding, unstructured care pathways, equipment supply levels that do not meet need, low staff-to-patient ratios and staff shortages, and the inability to deliver quality multidisciplinary care. The need for clinical guidelines and service specifications was highlighted as requisite for reducing variation in clinical care.

Conclusions: Systemic factors influence the needs-based provision of non-invasive ventilation for people with neuromuscular disorders. Development of clinical guidelines for Australia and New Zealand, dedicated funding for respiratory services for people with neuromuscular disorders, and specialist clinician training are important for equitable and high quality non-invasive ventilation care.

delivering quality non-invasive ventilation services to people with neuromuscular disorders.

Methods

We used a qualitative general inductive approach, informed by a critical realism ontological paradigm with contextualist epistemology,¹⁷ to explore the experiences of Australian and New Zealand clinicians who provide non-invasive ventilation services to people with neuromuscular disorders. Critical realism is used in health services research to frame, identify, and understand complex phenomena. An equity of health care framework, which examines health service delivery from the systems (macro-level), organisation (meso-level) and health professional (micro-level) perspectives, guided our analysis.¹⁸ Our study is reported in alignment with

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the Consolidated Criteria for Reporting Qualitative Health Research (COREQ).¹⁹

Recruitment

Clinicians in the fields of respiratory, sleep, and paediatric medicine who provide non-invasive services to people with neuromuscular disorders in Australia or New Zealand were invited to participate during 1 October 2017 – 31 May 2018, using the 2017 Australasian Sleep DownUnder Conference delegates email list (all registered delegates were invited by email) and by snowball recruiting of conference participants. Recruitment ceased when data saturation was reached.²⁰ A semi-structured interview guide ([Supporting Information](#)) was piloted by two clinicians experienced in non-invasive ventilation (authors AN and AP).

Data collection

The research team included health professionals in the disciplines of physiotherapy, nursing, and general and respiratory medicine with a combined forty years of qualitative research experience. Four authors (MAP, BJ, HD, TI) each led focus groups as part of a workshop at the Australasian Sleep DownUnder Conference. Two focus groups included Australian clinicians, two groups New Zealand clinicians; each group included five or six participants. Zoom interviews with individual participants who could not attend the focus group sessions were undertaken by BJ or MAP between 20 November 2017 and 31 May 2018. Informed written consent was obtained from participants prior to each interview. The interviews were audio-recorded and transcribed verbatim by a commercial transcription service, and a summary of the identified themes was provided to participants to confirm data interpretation (member checking).¹⁷

Analysis

Transcripts were stored and coded in NVivo 11 (QSR International). The data were independently analysed by authors BJ and MAP, using an iterative, semantic, and inductive approach.¹⁷ Audio recordings and transcripts were repeatedly listened to, read, and categorised. Reflective research notes were included as part of the analysis.²⁰ Data and investigator triangulation, incorporating independent parallel coding and consistency checks with the entire research team and participants, were undertaken²⁰ for iterative revision and refinement of themes.¹⁷ Our description of the participants provides inference transferability.²⁰

Ethics approval

The University of Otago Human Ethics Committee (Health) approved the study (H17/055).

Results

A total of 23 participants attended the four focus group sessions (mean duration, 92 minutes; range, 86–98 minutes) and five people participated in individual interviews (mean duration, 56 minutes; range, 49–60 minutes) ([Box](#)). The participants were clinical nurse specialists, advanced respiratory and critical care therapists, respiratory and sleep registrars and consultants, and paediatric sleep fellows involved in acute tertiary care, sleep clinics, and respiratory outpatient care; all were based in major urban centres. Two major themes were identified by our analysis: decision making for current practice, and resource constraints. In addition to the quotes included here,

Demographic characteristics of the 28 participants in the focus groups and interviews

Characteristic	Number
Gender	
Women	17
Men	11
Age group (years)	
20–29	2
30–39	8
40–49	11
50–59	6
60–65	1
Ethnic background*	
Australian (European)	9
New Zealand European	9
Asian	8
Pasifika	2
African	1
Profession	
Physician	18
Nurse	5
Physiotherapy	4
Physiologist	1
Location: Australia	14
New South Wales	3
Queensland	3
South Australia	3
Victoria	2
Western Australia	3
Location: New Zealand	14
Central	4
Northern	4
Te Manawa Taki	4
Te Waipounamu	2
Clinical practice (years)	
1–5	2
6–10	4
More than ten	22

* Multiple responses possible. ♦

further participant comments are included in the [Supporting Information](#).

Decision making for current practice

The rationale, policy, procedure, and use of guidelines for providing non-invasive ventilation differed between clinicians, who reported during the sessions and interviews that they were based in a variety of hospitals, health regions, and locations. Some participants indicated that the need for therapeutic non-invasive

ventilation was determined primarily by individual symptoms, such as weight loss, or by oximetry results or a sleep study. Others used a combination of NSW and overseas guidelines, personal experience, and symptom presentation to guide decision making. Participants suggested that updating older guidelines or developing new Australian and New Zealand clinical non-invasive ventilation guidelines and service specifications would be “very valuable”. They commented on the benefits of guidelines for reducing regional variations in care delivery and benchmarking practice standards that provide a basis for resource allocation to ensure safer and more equitable standards of care:

It is important we get national guidelines to standardise that this is the expected standard of care. Focus group 1 (New Zealand)

The other thing that's lacking is a standard policy on what type of equipment these people need at different stages of their disease. Each state seems to have adopted its own policies, and we've done the same, and they're not consistent across the country. Focus group 3 (Australia)

There isn't a framework for implementing non-invasive ventilation services in new institutions. And that's a problem. Focus group 3 (Australia)

While participants recognised the signs and symptoms that indicate clinical need for non-invasive ventilation, they were not as confident in identifying indications and complications for people with neuromuscular disorders. Most participants had gained confidence in this specific area from experiential learning and *ad hoc* mentoring, rather than tailored courses. They noted that recognition of respiratory failure in neuromuscular disorders required specific evidence and understanding, but their formal training had:

... relatively superficial coverage of the topic. Focus group 3 (Australia)

Resource constraints

Resource constraints broadly affecting access to and quality of care were mentioned:

Isn't everyone underfunded and understaffed? Focus group 1 (New Zealand)

Despite clinical need, access to non-invasive ventilation was often difficult. Some participants reported that their organisations had capped rather than needs-based funding, which became a more pressing problem later in the financial year. All noted the long waiting times for respiratory services experienced by people with neuromuscular disorders. Participants felt their decision-making was undermined by their organisations' financial priorities:

We put [non-invasive ventilation resourcing] higher to managers ... they just do not want to know. The problem is, until there's a national mandate from government saying this is the expected standard, it's not going to happen. Focus group 1 (New Zealand)

Participants in services with dedicated neuromuscular disorders budgets reported fewer problems providing care, while others who relied on sleep or respiratory departmental

budgets discussed the ethical dilemma and opportunity cost of deciding whom to give priority for treatment. They struggled to match clinical need to the limited models of non-invasive ventilation available, and for safety reasons could often only provide devices with battery back-up to people who were not dependent on non-invasive ventilation. The sustainability of non-invasive ventilation service provision was uncertain:

We only have a set number, the number of people with need keeps increasing, but the system is not designed in a way to try and cope. Focus group 2 (New Zealand)

Participants argued that a national service specification would enable the central pooling of resources and optimise use of staff time while ensuring:

... equitable funding and service provision, rather than [everyone] reinventing the wheel. Focus group 3 (Australia)

Staff shortages and large caseloads left participants demoralised about their ability to deliver best practice. They recognised that they and other staff were working to meet impossible expectations in order to fill service gaps:

You don't have the time, you don't have the staff. Focus group 4 (Australia)

Quality of care and access to services was also compromised by unstructured care pathways and poor multidisciplinary collaboration. This was evident when people with neuromuscular disorders were “lost” during the transition from paediatric to adult services, or after changes in residential type or geographic area. Outcomes were better in neuromuscular disorders multidisciplinary clinics because of streamlined referral processes, coordination of care, and communication between health professionals. Participants commented that without a clinical leader, roles and responsibilities were undefined, leading to inefficient communication and action, and delaying the provision of non-invasive ventilation.

The criteria that people with neuromuscular disorders must satisfy for publicly subsidised non-invasive ventilation differed between health areas and states, and the threshold for means testing also varied by region. Participants noted that non-invasive ventilation was more readily available to people with accident-related injuries (funded by insurance) than for people with neuromuscular disorders. Even with public subsidies, people could have financial difficulties, sometimes mitigated by charitable organisations, but participants suggested this was unethical, arguing that public donations should be used only for counselling and improving the skills of patients and caregivers and for other specific areas of need:

Counselling, support, or for better education for the families, or for things the health board would never pay for. People's charitable donations should not be subsidising the government's poor health care funding. Focus group 3 (Australia)

Distance from health services and higher care-related costs, often associated with other socio-economic barriers, were greater for people living in rural areas, and were not always ameliorated by telehealth care. Participants suggested that resources for non-invasive ventilation access and care were dictated by demand, resulting in an inequity between urban and rural areas, a “postcode lottery”, whereby:

... transport even when they are well is difficult, let alone when they're deathly ill. Individual interviewee 4 (Australia)

The lack of non-invasive ventilation clinical guidelines, service specifications, and dedicated funding for people with neuromuscular disorders meant that lives were at risk:

It'll take someone to die before it is taken seriously. Focus group 2 (New Zealand)

Discussion

We found that clinicians are concerned about differences in the access to and quality of non-invasive ventilation services. Our companion study of the experiences of people with neuromuscular disorders found that they reported similar health system, organisational, and health professional factors affecting non-invasive ventilation services.¹⁵

System (macro-)level factors

The priority level of Australian and New Zealand services for people with neuromuscular disorders was unclear and the lack of dedicated funding resulted in differences in access to non-invasive ventilation resources. Without a defined care pathway, people were “lost” as they shifted between types of service, residential type, or geographic location. People with neurological and complex health conditions are at greatest risk of poor transitions between health services.²¹ Participants confirmed previous reports that differences in care were worse for people in rural areas,^{10,15,22} but made no specific references to differences by ethnic background.

Organisational (meso-)level factors

Participants could not consistently secure organisational resources to meet the clinical needs of people with neuromuscular disorders. Barriers to delivering high quality non-invasive ventilation care included machine maintenance, consumables supply, transitions between services, limited pre-registration and subsequent professional development training, and variable education for people with neuromuscular disorders and their caregivers. These factors were compounded by low staff-to-patient ratios and staff shortages. People with neuromuscular disorders have reported similar organisational problems.¹⁵ Participants recognised the value of multidisciplinary teams for enhancing access to allied health and quality of care. People with neuromuscular disorders cared for by multidisciplinary teams experience a higher quality of care and life, and their survival rates are better.^{23,24}

Health professional (micro-)level factors

The lack of structured opportunities for interprofessional collaboration in many services results in inefficient communication, clinician burden, and risk of service failure. Role clarity and good leadership, with structured multidisciplinary pathways, can minimise these risks and enhance clinician effectiveness.²³ Factors affecting the quality of individual patient-clinician relationships were not discussed by participants, but these relationships also affect quality of care,^{11,15} as do system and organisational constraints.²⁵ Positive patient-clinician relationships can mitigate these constraints; for example, some participants went beyond their core role to

actively assist with access to resources. Conversely, poor patient-clinician relationships can intensify the distress of people with neuromuscular disorders.^{11,15}

Our participants identified that developing Australian and New Zealand or national guidelines and service specifications would support best practice and equitable care delivery, and would be an opportunity for addressing some of the factors responsible for variability in non-invasive ventilation care for people with neuromuscular disorders. To be effective, guidelines should be developed in an equity framework and in partnership with multidisciplinary clinicians and service users²⁶ and updated regularly according to new evidence. Providing adequate resources to overcome barriers to service implementation is also important, together with the establishment and training of multidisciplinary teams.

Limitations

Canvassing the views of Australian and New Zealand clinicians on the provision of non-invasive ventilation to people with neuromuscular disorders, together with a health equity framework analysis, is an effective approach to exploring systematic health service factors. The views of a small group of clinicians interested and experienced in this topic, although consistent across clinicians from both countries and similar to those of our companion study of people with neuromuscular disorders,¹⁵ cannot be broadly generalised, particularly as the representativeness of the participants is uncertain. We undertook our study before both the coronavirus disease 2019 (COVID-19) pandemic and the recent restructuring of the New Zealand health system; the impact of each on service provision is unknown.

Conclusion

Understanding clinicians' perspectives of non-invasive ventilation services for people with neuromuscular disorders in Australia and New Zealand provides insights into variations in quality of care. We identified factors at the system, organisation, and health professional levels. Clinical guidelines, together with dedicated funding for neuromuscular, multidisciplinary respiratory services and clinician training are important for supporting equitable and high quality non-invasive ventilation respiratory care in Australia and New Zealand.

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Supporting Information

Additional Supporting Information is included with the online version of this article.