

April 29th Workshop

Improving the Experience of Patients Requiring or at Risk of Long-Term Mechanical Ventilation Final Report July 2010

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Executive Summary

Introduction

Canadian and international epidemiologic trends indicate that the number of patients at risk for, or requiring, long-term ventilation is rising and will continue to increase. International reports indicate patients that require long-term mechanical ventilation account for up to 10% of all mechanically ventilated patients in intensive care units (ICUs), 40% of ICU bed days, and 50% of ICU costs posing substantial burden on constrained critical care resources. In Canada, availability of inpatient bed capacity in specialized weaning facilities and institutional long-term care is limited meaning many long-term ventilated patients have protracted ICU stays.

The Meeting

We conducted a workshop drawing together a community of key stakeholders to: (1) identify issues and priorities arising from the recently developed Canadian guidelines for long-term ventilation; (2) inform key stakeholders of current best practice models; (3) determine goals, objectives, and methods for an programmatic agenda focused on optimizing seamless and timely transitions through the continuum of care; and (4) facilitate collaborative relationships and partnering for future research projects.

Seventeen invitees, three international speakers and five steering group members attended the full day workshop and a further seven invitees from the home ventilation guideline committee joined the workshop in the afternoon.

Key Points from Interactive Collaborative Discussion

Practice Models (Acute Care)

Key features of existing models in Canada included:

- Poor recognition of the at-risk population in acute care
- Patients generally remain in an ICU within an acute care hospital
- Lack of rehabilitative focus in ICUs
- Low priority due to competing needs of acutely-ill patients

The optimal model for the future would include:

- Early identification of patients at risk of prolonged mechanical ventilation on admission to ICU;
- Immediate implementation of preventative strategies related to active rehabilitation;
- Protocolized best practices including mandated checklists at specified time-points; and
- Improved communication not only across disciplines, specialties and care teams but also with families and patients.

Barriers to Patient Transfer across the Care Continuum

Identified barriers included:

- Low volume/high cost population means low visibility/lack of appeal to policy makers and funders
- Population spans acute care and community sectors whereas funding is usually institutional as opposed to patient specific further impacting on funding availability
- Lack of overall vision, programmatic approach, and leadership
- Need for baseline data/registries and the need for improved communication across the continuum and transition points

Improving Transitions across the Continuum of Care

Areas of need identified included:

- Consistent definitions of transition points achieved through expert consensus
- Best practice guidelines applicable to transition phases with accompanying education and development of appropriate interdisciplinary skill sets
- Transition points should be highlighted as triggers for patient/family/care team communication to inform care mapping.
- Health policy needs to address the transition points in relation to funding care mapping and case management.

Knowledge Generation Priorities and Opportunities

There is a pressing need for a minimum national dataset to provide information on changing epidemiologic trends and patient outcomes for patients within the ICU, in other hospital or institutional settings and receiving ventilation in the home

Other priorities and opportunities include:

- Description of current uptake of evidence-based practices
- Scoping of practice models with evaluation of patient outcomes for various models.
- Qualitative description of the patient experience along the care continuum
- Further information on appropriate timing and dosing of rehabilitation
- Better evidence describing appropriate times for initiation and withdrawal of non-invasive ventilation for home ventilated patients

Priorities and Opportunities for a Policy Agenda

Immediate priority is to get the attention of the provincial Ministries of Health and other regional health authorities to facilitate appropriate funding and resource allocation. Public awareness also needs to be raised. Ministries and other organizations should be approached with a defined strategy that identifies ways to realign or reinvest resources as opposed to a request for additional monies.

Priorities and Opportunities for Knowledge Translation and Network Creation

The primary need identified was to perform a gap analysis to understand why known knowledge is not translated into practice using a framework to evaluate issues related to this patient population.

Recommendations for Future Directions

- **Provincial Leadership:** Establish interdisciplinary leadership within each province that can generate an action plan to operationalize the priorities and opportunities identified through this workshop
- **Expanded Community of Excellence:** Continue to create our national community of excellence to sustain collaborative sharing of expertise through further identification of experts and interested parties. Generate a programmatic approach to improving care across the continuum.
- **Population-focused Agenda:** Establish a program that will address the priorities and questions identified by the group. Long-term goals include: (1) undertaking targeted projects that addresses current gaps that will then be translated into practice; (2) increasing use of current best practices based on quality research; and (3) encouraging coordinated, focused data collection relevant to long-term ventilated patients.

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Background

For some patients, the process of liberation from mechanical ventilation and restoration of normal breathing (referred to as weaning) poses substantial difficulty and results in prolonged or permanent dependence on mechanical ventilation. International reports indicate patients that require prolonged mechanical ventilation (≥ 21 days) account for up to 10% of all mechanically ventilated patients, 40% of intensive care unit (ICU) bed days, and 50% of ICU costs [1, 2]. A smaller proportion of patients will continue to require ongoing ventilatory assistance that necessitates admission to a long-term assisted ventilation facility [3]. The main types of diagnoses for patients requiring prolonged ventilation include acute lung injury (ALI) or acute respiratory distress syndrome (ARDS), chronic obstructive pulmonary disease (COPD), restrictive lung disease, and non-obstructive ventilatory failure due to degenerative muscular diseases, thoracic cage deformities and high spinal cord injury.

Awareness of epidemiological trends for mechanical ventilation is important as there are significant financial and resource implications for healthcare systems and organizations as well as patients and their families. The cost of mechanical ventilation has been estimated at \$1522 per day adjusted for patient and hospital characteristics in the US [4] and €2110 per day (unadjusted) in a recent European evaluation [5]. In Ontario, based on Ontario Case Costing Initiative 2004/05 data, the total per diem costs of an ICU bed in an Academic Health Sciences Centre was estimated to be \$3745 and \$2024 for an ICU bed in a community hospital [6]. One large, cross sectional US study reported patients receiving mechanical ventilation for a minimum of four days accounted annually for seven million hospital days and \$16 billion. The costs of prolonged mechanical ventilation are not only financial; long-term physical and psychological consequences affect quality of life and may impose substantial symptom burden [7, 8]. Prolonged ventilator dependence, reduced mobility, as well as anxiety and depression may occur due to the absence of an interdisciplinary, rehabilitative approach common to the majority of ICUs [9].

Specialized weaning facilities are one organizational model proposed to facilitate efficacious and cost effective weaning resulting in reduced long-term ventilator dependency, increased survival, and improved health-related quality of life [10, 11]. Access to this type of facility may not be available to all patients due to limited bed numbers and disparities between the geographical location of the patient, their family and the weaning facility. Those patients that remain ventilator dependent and unable to access specialized weaning or long-term ventilation facilities must remain within an ICU as an alternate level of care (ALC) patient. ICUs generally are not structured or resourced to provide the interdisciplinary rehabilitative services that are a feature of weaning and long-term ventilation facilities.

In Ontario the Ministry of Health and Long Term Care, as part of the Critical Care Transformation Strategy, commissioned the Chronic Ventilation Strategy Task Force to examine issues pertinent to the needs of chronically ventilated but medically stable patients. Using a one-day point prevalence survey conducted in November 2005, the Task Force identified 45 medically-stable patients in Ontario ICUs who had received mechanical ventilation for an average of 141 days [6]. These patients remained ICU in-

patients as no adequate alternative setting was available to them. Based on this data the Task Force estimated 1000 to 2000 additional ICU admissions could be accepted to current facilities if these patients were discharged in a more timely fashion. Subsequently, a second survey of Level 3 ICUs in Ontario conducted in August 2007 identified 70 patients receiving long-term ventilation in 30 ICUs with an average of 2.3 patients per ICU [12] amounting to 25,500 ICU bed days. The Critical Care Secretariat Projections informed by the work of the Task Force estimated the demand for ICU beds for this patient population will increase annually by 4.3% with a total increase of 107% over the next 25 years, placing an overwhelming burden on intensive care services in the future [6].

Rationale

Using the Ontario example described above, it is evident that the number of patients at risk for, or requiring, prolonged and long term mechanical ventilation will continue to increase, placing a burden on existing resources. Also it is likely that specialized services for this patient population will remain constrained. Available resources must be used appropriately and strategically to offer the greatest benefit to this vulnerable patient population. At present there is no Canadian-wide data available or network of clinician experts and key stakeholders in existence to inform decision-making and policy for this patient group. Knowledge translation from international and Canadian models of best practice and centres of excellence must occur to facilitate better health and quality of life for patients at risk or requiring prolonged mechanical ventilation.

Two international consensus conferences focused on prolonged and long-term mechanical ventilation identified a lack of empirical data describing this patient population and the need for further studies to identify factors contributing to ventilator dependence, to determine effective weaning management and to describe outcomes for patients experiencing prolonged mechanical ventilation and difficulty weaning [13, 14].

Meeting Objectives

The primary objective of this workshop was to draw together a national community of key stakeholders, decision-makers and clinician experts in the management of patients at risk of or requiring prolonged and long term mechanical ventilation to facilitate better prevention, early detection and treatment, and effective management of this patient population

The goals of the workshop were to:

- (1) identify current issues and priorities arising from the recently developed Canadian guidelines for the management of home mechanical ventilation;
- (2) inform decision-makers and key stakeholders of current best practice models;
- (3) determine goals, objectives, and methods for a programmatic agenda focused on optimizing seamless and timely transitions through the continuum of care for patients requiring prolonged mechanical ventilation; and
- (4) facilitate collaborative relationships and partnering for future projects.

The Event

This invitation-only workshop was held on April 29th, 2010 immediately prior to the Canadian Respiratory Conference in Halifax, Nova Scotia. Invitations were sent to Canadian interprofessional leaders within ICU, Respiriology, and related Specialties combined with a spectrum of relevant people across the continuum of care. Prior to the workshop we conducted a half day discovery meeting (January 31st, 2010) for the steering group members. The objective of this meeting was to explore and develop a set of strategies for the establishment of a Canadian Community of Excellence in Prolonged and Long term Mechanical Ventilation as well as to plan the April workshop. In addition, prior to the workshop we sent out a pre-meeting questionnaire to all invited attendees to obtain written input into the objectives of the workshop.

Seventeen invitees, three international speakers and five steering group members attended the full day workshop and a further seven invitees from the home ventilation guideline committee joined the workshop in the afternoon. Workshop activities comprised formal presentations from two local speakers; Dr Fraser presented an overview of the current Canadian practice models and Dr McKim presented an update on the current status of the home ventilation guidelines. Three international speakers presented the US and European practice models and perspectives on research priorities for management of this patient population in both acute care and long term ventilation. Morning and afternoon break out sessions were held to address the following key questions.

1. What models exist for creating the best and most efficient chronic care in today's ICU and how do we create the "optimal model" and implement it across Canada?
2. What are the barriers and key issues in your region to transferring patients from the ICU to a weaning or long-term ventilation centre?
3. How do we improve transitions across all continuums of care, and what are the priorities for improvements and the feasibility of potential strategies?
4. What are the knowledge generation priorities we need to consider and what opportunities exist to develop an accessible country wide network for data collection pertinent to our patient populations?
5. What are the priorities and opportunities for a policy agenda?
6. What are the priorities and opportunities for knowledge translation and network creation?

Vision

Our vision for this meeting was to create a Canadian Community of Excellence focused on patients at risk or requiring prolonged and long term mechanical ventilation (Figure 1). This vision encompasses clinical, research, policy, and knowledge translation priorities as well as generating inclusivity to incorporate:

- the continuum of care (paediatric to adult, at-risk patients in the community, acutely ill patients progressing to prolonged mechanical ventilation, long-term ventilation, end of life care, home versus institutional care);
- national geography;
- intensive care and respirology communities
- interprofessional collaborations
- the patient/client voice

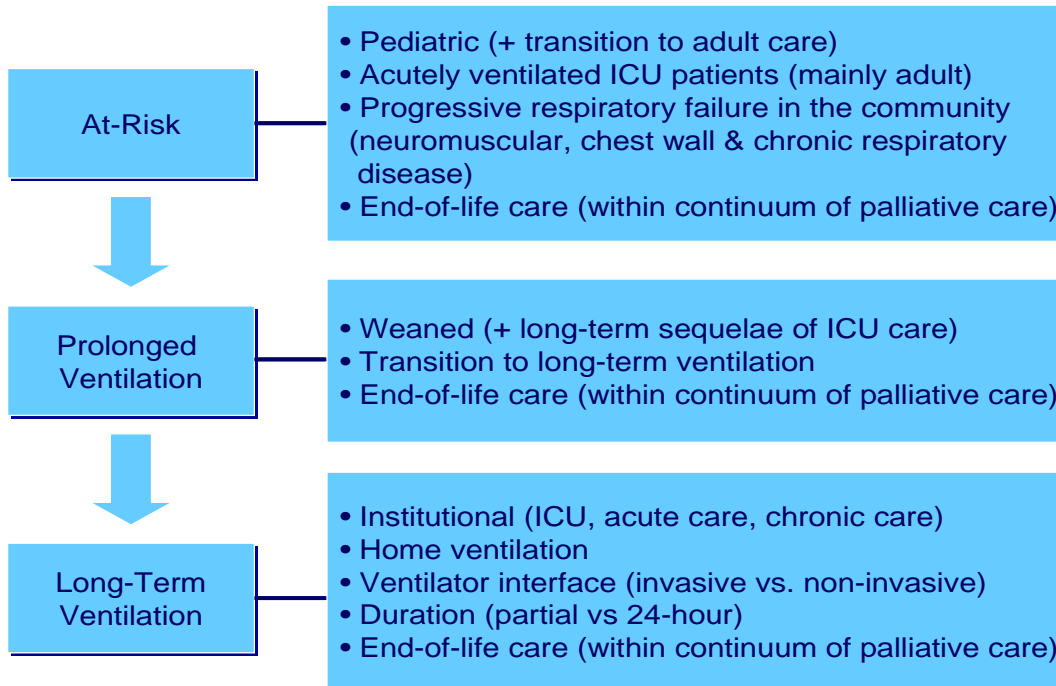


Figure 1 Defining the Patient Population

Discussion

Definitions

The following definitions are recognized as pertaining to the patient population discussed at the workshop.

Prolonged Mechanical Ventilation: ≥ 21 consecutive days of ventilation for ≥ 6 hours per day (includes NIV use if ≥ 6 hours per day).

Prolonged Acute Mechanical Ventilation: ≥ 4 days of MV; ICD-9 code 96.72

Chronic Critical Illness: ≥ 10 days of MV without imminent death or extubation (72 hrs)

Long Term Ventilation: ≥ 30 consecutive days of ventilation and an extremely low to no probability of weaning success

Practice Models

The Canadian Perspective

Tremendous heterogeneity exists in the current care models for patients at risk or requiring prolonged mechanical ventilation and long-term care. Using the example of three provinces in Canada we noted differences in capacity of the various ICU systems, the presence of multiple ICUs in some hospitals, and a lack of proportionality for ventilator bed capacity to population numbers. Various models exist including designated Centres of Weaning Excellence in some provinces (likely the minority) and designated beds adjacent or within ICUs for patients requiring prolonged mechanical ventilation whose care is generally managed by the same team covering the ICU (Table 1)

For patients requiring long-term ventilation, similar heterogeneity of care models exists. Quebec is the only province to offer centralized telemetry support for home ventilation. British Columbia has a client-driven Provincial Respiratory Outreach Program (PROP). Ontario uses a centralized model for equipment and technical support but decentralized care. Funded beds for long-term ventilation are available in every province, yet numbers are insufficient to meet demand (Table 2).

Table 1: Prolonged Mechanical Ventilation

	Quebec	British Columbia	Ontario
Population (2006) (million)	7.5	4.1	12.1
ICU units/hospitals	45/36	42/ --	213/126
Ventilation-capable beds /100,000	7.2	3.5 to 6	8.7
Designated Centre of Excellence for Weaning	Montreal Chest Institute	No	Toronto East General
Extended – ICU-based weaning model	Jewish General Hospital	Burnaby General Hospital	London Health Sciences
Paediatric hospital-based programs	Yes	Yes	Yes

Table 2: Long Term Mechanical Ventilation

	Quebec	British Columbia	Ontario
Provincial home ventilation program	Yes	Yes (client-driven)	No
Centralized ventilator equipment pool & technical support	Yes	Yes	Yes
Centralized telemedicine support	Yes	No	No
Designated Centre of Excellence for Chronic Ventilation	Montreal Chest Institute	No	Westpark
Funded long-term ventilation beds	Yes	Yes	Yes

Commonalities within models of care across Canadian provinces are gaps or challenges to the continuum of care. Examples of barriers to optimizing the care continuum include: lack of timely identification of patients at risk of prolonged mechanical ventilation; limited downstream capacity resulting in prolonged ICU stay; an overall imbalance of supply versus demand at every stage of the continuum; and delays in discharge to home due to a lack of equipment, training and services. Another commonality across Canada is the geographical challenge associated with large distances combined with small patient numbers within geographical regions.

The US Perspective (Prolonged Mechanical Ventilation in the Acute Phase)

Existing published data indicate the proportion of patients requiring prolonged mechanical ventilation is steadily rising in the US [15, 16]. Projections indicate by 2020 approximately 600,000 patients per year will require mechanical ventilation for ≥ 7 days. These trends indicating growth of this patient population are not purely the result of growth in the age of the population but also represent advances in our ability to delay or prevent mortality in the ICU. Additionally up to 40% of ICU resources may be spent on these patients even though they contribute only 10-15% of the ICU population [17]. Costs to the health care system continue after discharge with hospital readmission rates reported to be as high as 40% [18].

Various care models exist within the US for patients requiring prolonged mechanical ventilation. A baseline care model is the continuation of usual care within an acute ICU. This model is not optimal as the care focus remains acute and the needs of patients requiring prolonged mechanical ventilation may not be prioritized. Some institutions transfer patients to an intermediate care unit where responsibility for care is assumed by the floor team. Again, this model may not be appropriate if the care team does not have sufficient expertise in the management of weaning and provision of a rehabilitative focus.

The delivery of protocolized rehabilitation based care either within the acute ICU or specialized post-ICU venues are preferred models of care. In the US, patients may be transferred to respiratory units within the acute hospital or transferred to a long-term acute care (LTAC) hospital situated either within the acute hospital or as a free-standing

institution (Figure 2). Home ventilation is not a key feature of the US system due to current funding models within the health care system.

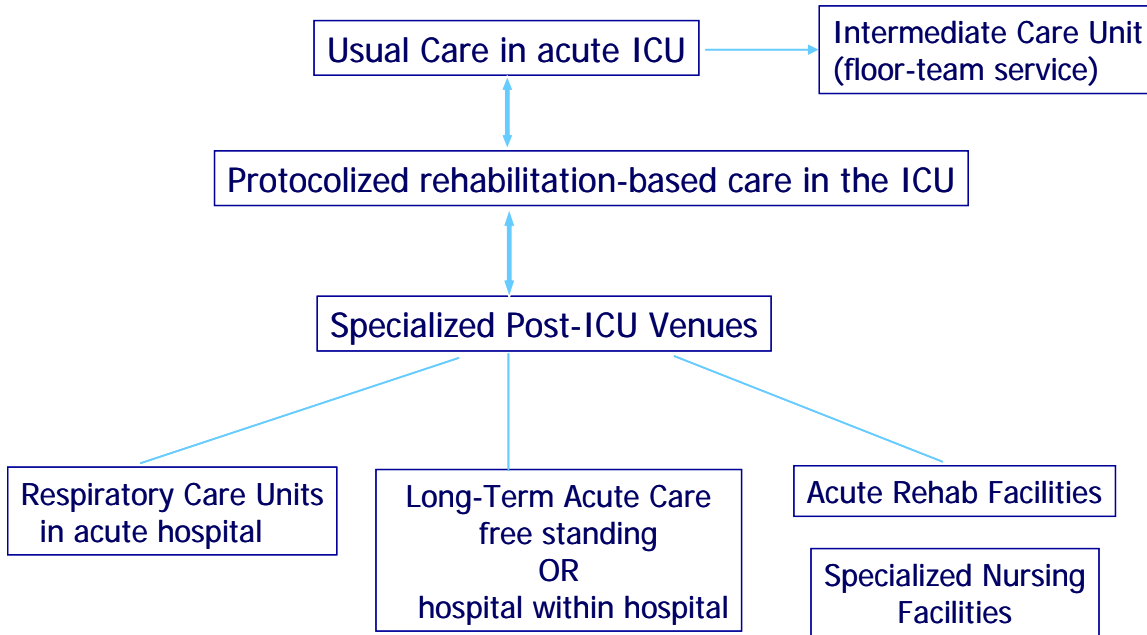


Figure 2: Evolution of care Venues in the United States

The European Perspective (Long-Term Mechanical Ventilation)

Variability of practice models across European countries is a key feature in the provision of care for patients requiring long term ventilation. Models of care have been influenced by historical factors such as the polio epidemic and the adoption of non-invasive ventilation (in the community prior to adoption in the ICU) and service provision including funding models. The prevalence of home ventilation varies across countries and regions for reasons not related to gross domestic product, funding structure, health system or patient diagnosis.

Ongoing care for patients receiving long term ventilation is also highly variable. Patients receive care from a variety of care-givers who receive a range of training that may not always be optimal. Ongoing follow up for patients is sometimes systematic and well organized but the majority of patients have variable or sporadic follow up care. Epidemiologic trends indicate the number of patients receiving home mechanical ventilation is increasing in all European countries. The profile of patients is also changing with more patients requiring home ventilation for obesity hypoventilation syndrome and in the 70+ age group.

Summary of Discussion (morning sessions)

Creating the Best and Most Efficient Model for Chronic Care in Today's Intensive Care Unit

Discussion on current models of care identified poor recognition of the at risk population in acute care. The most prevalent model in Canada for management of patients requiring prolonged mechanical ventilation is one whereby the patient remains in an ICU within an acute care hospital. Care is generally not focused on rehabilitation; frequently these patients are prioritized low in terms of time spent organizing and evaluating care due to competing priorities from acute care patients.

Optimal Proactive Model

Discussion of the optimal proactive model proposed for adoption across Canada comprises:

- (1) Early identification of patients at risk of prolonged mechanical ventilation on admission to ICU;
- (2) Immediate implementation of preventative strategies related to active rehabilitation;
- (3) Protocolized best practices including mandated checklists at specified time-points; and
- (4) Improved communication not only across disciplines, specialties and care teams but also with families and patients.

Discussion group participants acknowledged that the location of care delivery (within ICU, versus adjacent to ICU, versus separate defined location) may not be *as* important if the above four principles were adhered to as a model of practice. However a separate location offers the advantage of not being counted as ICUs beds available for surge capacity. Additionally organization of care is dependent on practicalities and funding which may be difficult to influence.

Implementation of the Model

Experienced leaders within the group recognized the published failure of strategies such as implementation of evidence-based guidelines, audit and feedback, and education in the ICU context. The primary implementation strategy designed to optimize uptake of the optimal proactive model of care suggested by the group focused on pay for performance. The possibility of tying performance to accreditation standards was suggested as an effective strategy. Possible incentives could be at both the staff and institutional level however, performance needs to be measured across health care systems to generate pay for performance criteria. Performance outcomes could be used as a justification for costs such as creation of an advanced practice role. Other strategies suggested to translate existing knowledge into practice was the use of peer influence in the form of local champions. A contagion model was proposed whereby pilot sites and or projects would be used to generate and then disseminate best practices for this patient population.

Barriers to Transferring Patients from the ICU to Weaning and Long-Term Ventilation Centres or Home

The discussion group identified multiple barriers to transitioning patients out of the ICU into a post-ICU facility. Prioritization of these barriers posed difficulties however, one barrier is the nature of the patient population i.e. dealing with a low volume, high cost group that may not be politically attractive to policy makers, meaning few funds are available. This patient population also spans both acute and community healthcare sectors so that funding is required from diverse and sometimes competing sources. One proposed solution to this barrier was to maintain a client-driven focus that will make the client voice heard by policy makers.

A lack of overall vision or programmatic approach for a system of care for this patient population was identified as another significant barrier. There is a need for political agreement that provision of an appropriate system of care for this patient population across the continuum is an important issue that will be appropriately funded to enable the needs of these patients to be met. This vision needs leadership and multiple champions across the care continuum and geographical locations.

Institutional barriers were also noted. Funds are generally attracted to institutions as opposed to patients. This means that funds do not follow patients creating disconnects in the continuity of care. Hospital administrations are focused on their meeting their own budget demands as opposed to facilitating transition of patients and the accompanying transfer of funds. Additionally there is a lack of human resources dedicated to this patient population. Professionals from all relevant disciplines need to be appropriately trained and remunerated to manage this patient population both in the acute care and community setting.

Another identified barrier was the lack of a registry or database containing information regarding health care providers and patients. Improved communication processes are required to facilitate seamless transitions. A registry is needed that will be available to multi-professional providers across units and institutions. This registry should contain information on patient care maps accessible to health care professionals. Agreement on care plans or care maps that incorporate the transition across institutions will require clear communication and a uniform structure. Information of health care resources and providers also should be readily accessible to patients and their families so that individuals know where to get help in a timely manner if needed. Care maps should also include palliative care decision making so those ends of life decisions are documented.

Improving Transitions across the Continuum of Care

Identification of Transition Points

The group identified the following transition points that are important within the continuum of care. Transition points may reflect a point in time or specific event or may be related to a transition in care location.

Transitions include from:

- (1) being 'at-risk' to 'requiring prolonged or long term mechanical ventilation. This is the point when the patient is first offered (or initiated on) invasive or non-invasive mechanical ventilation
- (2) requiring mechanical ventilation in the acute phase of critical illness to requiring prolonged mechanical ventilation (≥ 21 days ventilation)
- (3) prolonged mechanical ventilation to long term ventilation (defined as extremely low to no probability of weaning success)
- (4) institutional care to care within the community (home/assisted living)
- (5) active treatment to end of life care (limitation of treatment escalation; active withdrawal of care)
- (6) long term or prolonged mechanical ventilation to acute critical care due to worsening medical condition/new onset of illness (reverse transition)
- (7) paediatric to adult (consider parents as well as child)

Barriers to Transition

Specific barriers to facilitating smooth transition between the above transition points included:

- (1) Communication and lack of a documented care map. Decisions may need to be made urgently due to rapid deterioration, and may not be fully informed by patient/family choice. Clinicians may lack experience or feel uncomfortable engaging in conversations about treatment options/palliative care. Clinicians also may lack decisional authority if decisions are required at unexpected time-points. Difference in values and cultural beliefs may also influence communication as well as issues surrounding health literacy.
- (2) Ethical challenges may arise. Lack of agreement on who should receive treatment and timing of end of life discussions. Rationalization of ICU care may be an issue.
- (3) Legislation: clinicians may not be comfortable withholding some treatment options. Initiation of ventilation as a life sustaining measure may occur even when documentation of patient wishes to the contrary may exist.
- (4) Definition of transition points as well as positioning of individual patients on the transition continuum (as described above) may not be clearly communicated across teams and specialties
- (5) Lack of best evidence for practice exists

Key Strategies

Consistent definitions of transition points achieved through expert consensus are required. Although some consensus definitions exist, further work is needed to ensure consistency of language. Best practice guidelines applicable to transition phases are needed. Education regarding current knowledge of best practice as well as development of appropriate interdisciplinary skill sets will encourage adoption of best practices. Transition points should also be highlighted as triggers for patient/family/care team communication to inform care mapping. Health policy needs to address the transition points in relation to funding care mapping and case management.

Canadian Thoracic Society Home Ventilation Guidelines

Background on Home Ventilation in Canada

Currently there are no comprehensive national data on home ventilation in Canada. Data gleaned from various small surveys suggest the most common indication for home mechanical ventilation is neuromuscular disease followed by obesity hypoventilation syndrome. Initiation of home ventilation may occur in the home for up to 20% of patients yet the majority of patients initiate home ventilation in the acute care sector including the ICU. The biggest barriers to receiving ventilation in the home are considered to be the cost of nursing care and the likelihood of remaining in an institution once ventilation is initiated.

Current Status of the Guidelines

The objective of the guidelines is to provide guidance for patients at risk or requiring ventilatory assistance, caregivers, and health care teams on the role of mechanical ventilation in the home. The guidelines will not only inform best practices but identify gaps in care and provide direction for future research on this topic area. At present the guidelines are in the final stages of review among the guideline team and will be sent out for external review, prior to publication.

Eleven areas to be addressed by the guidelines include:

- Airway clearance for ventilator assisted individuals
- Transition to home
- Amyotrophic lateral sclerosis
- Central hypoventilation syndrome
- Stable COPD
- Kyphoscoliosis
- Obesity hypoventilation syndrome
- Spinal cord injury
- Duchenne muscular dystrophy
- Muscular dystrophies other than Duchenne and myopathies
- Ethical consideration

Prolonged Mechanical Ventilation in Acute Care: a Perspective on Knowledge Priorities

Dr Shannon Carson

Dr Carson presented a succinct summary of his expert opinion on research priorities for patient at risk or requiring prolonged mechanical ventilation in the ICU. The issue of consensus on definitions for this patient population was again raised. Current studies use various durations of ventilation that interferes with standardization across studies. However the consensus definition of ≥ 21 days mechanical ventilation may be too long for ICU physicians wanting prognostic information prior to this time-point.

Research priorities were summarized in terms of prevention, management, communication, and post-acute care. Prevention requires translation of known effective practices such as prevention of deep vein thrombosis, ventilator associated pneumonia, central line blood stream infection, tight glucose control in cardiac surgery patients, non-injurious tidal ventilation, minimization of sedatives and use of weaning protocols and spontaneous breathing trials. The evidence related to early versus late tracheostomy was reviewed. Current data does not indicate improvements in hospital length of stay, the need for admission to a long-term care facility or 1-year mortality with early tracheostomy. Dr Carson discussed the need for more qualitative research describing the impact on the patient i.e. the burden of early tracheostomy versus endotracheal tube. More studies are required on interventions to prevent delirium. Early mobilization 1 to 2 days after ICU admission is another preventative measure that needs further study.

Management strategies that require further research include: mobilization protocols, delirium management, weaning protocols, protocols for prevention of nosocomial infection. There is a need to study the potential for rehabilitation for cognitive outcomes, the best approach to nutrition in this patient population, protocolized fluid management and the role of anti-inflammatory interventions such as statins. Translational research is required in the areas of endocrine function, polyneuropathy and immune dysfunction in chronic critical illness.

Communication between patients, family members and clinicians is another area that requires more research. Data suggest a serious disconnect between family members' perceived expectations for patient outcomes compared to physician perceptions. Dr Carson's group currently validating a prognostic model for determining outcomes of patients receiving ≥ 14 days mechanical ventilation; and conducting a randomized, controlled trial of the effect of implementation of a palliative care team conference and associated interventions on family-centred outcomes such as post-traumatic stress disorder and depression.

Care models also require further investigation. Previous research has identified different approaches to medical care (university vs community) influence patient outcomes. There is a need to identify optimal models of care within existent health care systems.

Long Term Ventilatory Support: a Perspective on Knowledge Generation Priorities

Dr Peter Wijstra

Dr Wijstra presented priorities for two groups of patients: chronic non-invasive positive pressure ventilation (NIPPV) for patients without, and with, chronic obstructive pulmonary disease (COPD). Baseline data on epidemiological trends is an important element of patient data. A registry of patients receiving NIPPV in the Netherlands created in 1991 and updated in 2010 demonstrates changing trends in the type of patients receiving NIPPV, with more patients with neurologic disease and older patients receiving NIPPV in 2010 compared to less recent data

Non-COPD patients

The type of patient that should receive NIPPV needs further clarification. More data is required demonstrating the effectiveness of chronic NIPPV for various patient categories including appropriate indicators for commencing chronic NIPPV. Little data exists to describe the effect of NIPPV for patients with obesity hypoventilation syndrome (OHS) on survival, quality of life and co-morbidity. Comparisons of the efficacy of CPAP compared to BIPAP should also be explored for OHS patients. Further work needs to clarify the most appropriate location to commence chronic NIPPV whether it is in the home, out-patient clinic, or in the ICU. The role of telemonitoring for home ventilation needs further exploration as do monitoring techniques such as sleep studies and the role of arterial blood gases compared to transcutaneous CO₂ monitoring. The efficacy of more advanced ventilator technology has not been explored in this patient population as well as the most appropriate length of ventilation e.g. six hours per night versus more or less.

Additional research questions that need answers for the non-COPD patient population include:

1. What are the pathophysiologic rationales behind the efficacy of NIPPV in various patient populations?
2. What is the role of mouthpiece ventilation and when should it be introduced?
3. What is the effect of lung volume recruitment on patient morbidity and hospital admission rates?

COPD Patients

Recent data from Dr Wijstra's group demonstrate improved oxygenation and ventilation, 6-minute walk test and FEV1 for COPD patients receiving rehabilitation plus nocturnal NIPPV compared to patients receiving only rehabilitation therapy. It is important to establish the primary goal of NIPPV for COPD patients. Further mechanistic studies are required that examine the effect of NIPPV on lung function including its effect on muscle rest, resetting CO₂ levels, improving sleep and improving lung function. Data is also required to confirm appropriate pressures for ventilation, the role of day versus nocturnal ventilation, the role of NIPPV after an acute exacerbation, and the combination of NIPPV with rehabilitation.

Summary of Discussion (afternoon sessions)

Knowledge Generation priorities and opportunities

Discussion on priorities identified substantial gaps in our knowledge of the prolonged and long term mechanical ventilation population in Canada. There is a lack of provincial or national data on three patient populations:

- a. Patients within the ICU;
- b. Patients in other hospital or institutional settings; and
- c. Patients receiving ventilation in the home.

The group felt there is a need for a minimum national dataset to provide information on changing epidemiologic trends and patient outcomes. This information would inform policy makers regarding funding and resource allocation. The group deemed it important not only to collect data on patient numbers and characteristics but also current uptake of evidence-based practices and care protocols for this patient population to inform the need for knowledge translation interventions. Ongoing follow up (past 21 days of ventilation) description of current practices should occur to provide information on the trajectory of care and practice.

Based on morning breakout discussions on the definitions of transition points, there is a need to develop these definitions using a Delphi design with workshop members plus other interested parties as participants. Workshop discussion also highlighted the variation in existing practice models across the country. There is a need to scope these practice models and evaluate patient outcomes for various models. The group also identified the need for more qualitative description of the patient experience along the care continuum. The role of rehabilitation was introduced as an important issue for further exploration. Questions related to the timing and dosing of rehabilitation in various patient groupings within the population need answering. Questions specific to the home ventilation population focused on the need for better evidence describing appropriate times for initiation of NIPPV as well as appropriate times to withdraw NIPPV.

Priorities and Opportunities for a Policy Agenda

The major priority identified for patients at-risk or requiring prolonged and long term ventilation is to get the attention of provincial Ministries of Health and other regional health authorities to facilitate appropriate funding and resource allocation. Raising the profile can be done in many ways including local and national media, and lobbying from existing related interest groups, and professional associations across various disciplines and specialties. There is an urgent need to get information related to long term ventilation into the public eye. Inclusion of survivor stories was one method suggested to raise public awareness.

Current attitudes and beliefs contributing to the existent 'low profile' of long term ventilation patients include:

- (1) Small numbers with no one disease to champion;
- (2) Decision makers have many other competing priorities;
- (3) Decision makers do not currently see how the needs of this patient population are aligned with current care and funding priorities;
- (4) Importance in terms of costs and quality of life are not recognized; and
- (5) Funding priorities for acute and chronic care may compete; this patient population fits within both sectors.

The group recognized the need to approach Health Ministries and regional authorities with a defined strategy that identifies ways to realign or reinvest resources as opposed to a request for additional monies. This would include a well-developed business case providing evidence of support for health care funding priorities. One option would be to identify existing funding priorities and align the needs of this patient group to this priority e.g. the wait time strategy. Another potential strategy to make the prolonged and long term ventilation patients more visible is to study other effective lobby groups such as organ donation and model their strategies. There is a need to link patient advocate groups and lobbying bodies to raise public awareness of long term mechanical ventilation as one option of care along the continuum of available options and to move forward with a shared goal and strategy. Another proposed strategy was to hire a public relation consultant to assist with raising awareness.

Priorities and Opportunities for Knowledge Translation and Network Creation

Key issues identified by the group were the need to perform a gap analysis to understand why known knowledge is not translated into practice using a framework to evaluate issues related to this patient population. Gap analysis will enable identification of barriers within the system such as communication issues, cultural gaps, role paralysis, and lack of understanding, access or usability of knowledge. Once the gap analysis has been performed then appropriate knowledge translation strategies can be selected. Examples of knowledge translation strategies include local champions e.g. rehabilitation rounds, involving the right stakeholders, networking with other clinicians and experts, education, sharing sentinel cases, advertising and reinforcement.

Recommendations for Future Directions

The interactive break-out discussions outlined in the discussion sections of this document identify many priorities and gaps in clinical practice and patient management, knowledge translation, and research that form an agenda of action.

Provincial Leadership

To continue to meet our vision it is important to establish interdisciplinary leadership within each province who can generate an action plan to operationalize the priorities and opportunities identified through this workshop. Considering the large geographical area patients originate from, it is essential that the provincial leadership teams have representatives from both the continuum of care, and different areas within the province.

Expanded Community of Excellence

Additionally we need to continue to create our national community of excellence through further identification of experts and interested parties in the field. Using this expertise, we plan to generate a programmatic approach to improving the care for patients at risk or requiring prolonged and long-term mechanical ventilation across the continuum. As well we will generate a prioritized work-plan to ensure the momentum and ideas from the workshop are implemented. Sustainable collaborative sharing of existing expertise with a collaborative clinical, research and policy agenda across the care continuum will:

1. improve the quality of life of this vulnerable patient population;
2. free up valuable and expensive ICU resources;
3. reduced health care costs;
4. provide ICU surge capacity for national emergencies such as pandemics; and
5. create collaboration and inform innovative research

Population-focused Agenda

Future directions will focus on establishing a program that will address the priorities and questions identified by the group. Long-term goals include: (1) undertaking targeted projects that addresses current gaps that will then be translated into practice; (2) increasing use of current best practices based on quality research; and (3) encouraging coordinated, focused data collection relevant to long-term ventilated patients.

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