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Research Article

Exploring factors affecting the timely transition of ventilator assisted individuals in Ontario from acute to long-term care: Perspectives of healthcare professionals

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Abstract

Rationale

Ventilator Assisted Individuals (VAIs) frequently remain in intensive care units (ICUs) for a prolonged period once clinically stable due to a lack of transition options. These VAIs occupy ICU beds and resources that patients with more acute needs could better utilize. Moreover, VAIs experience improved outcomes and quality of life in long-term and community-based environments.

Objective

To better understand the perspectives of healthcare providers (HCPs) working in an Ontario ICU regarding barriers and facilitators to referral and transition of VAIs from the ICU to a long-term setting.

Methods

We conducted semi-structured interviews with ten healthcare providers involved in VAI transitions.

Main Results

Perceived barriers included long wait times for long-term care settings, insufficient bed availability at discharge locations, medical complexity of patients, long waitlists, and a lack of transparency of waitlists. Facilitators included strong partnerships and trusting relationships between referring and discharge locations, a centralized referral system, and utilization of community partnerships across care sectors.

Conclusions

Insufficient resourcing of long-term care is a key barrier to transitioning VAIs from ICU to long-term settings; strong partnerships across care sectors are a facilitator. System-level approaches, such as a single-streamlined referral system, are needed to address key barriers to timely transition.

INTRODUCTION

Improvements in managing patients requiring prolonged mechanical ventilation have increased the number of ventilator-assisted individuals (VAIs) whose long-term survival remains dependent on technology. The estimated prevalence of VAIs reported in Canada in 2014 was 1.3/100,000 individuals.[1] Ventilator dependence can occur in patients with degenerative neuromuscular disease (NMD), spinal cord injury, thoracic restriction, parenchymal fibrotic conditions or severe obstructive lung disease.[2] Although medically stable, ventilator-dependent individuals occupy valuable ICU resources, including 50% of ICU costs.[3] Moreover, they require a rehabilitative rather than an intensive care environment.[4,5] The increased survival rate of VAIs, improvements in home ventilation technology and the need to reduce healthcare costs are important drivers of a system change toward transitioning such individuals out of intensive care. This transition from intensive to long-term care, or when possible, to a community-based environment for adult VAIs, reduces healthcare resource utilization.[6] For example, one study identified a 77% public cost savings per individual when VAIs were discharged to the community.[7]

In addition to being cost-effective, it is safe, associated with few adverse events, and may lower mortality.[6,8,9]

Notwithstanding the above, a national Canadian survey noted limited discharge options for VAIs, including a lack of long-term care facilities, home ventilation training services, and paid or unpaid caregivers.[10] Respondents also noted several perceived barriers to transitioning VAIs from the ICU, including a lack of beds, prolonged waiting times, and lack of a transition pathway.[10] The lack of a transition pathway results in the improper utilization of acute healthcare resources and underutilization of community services, thereby contributing to higher healthcare costs and compromising the quality of life of VAIs and their caregivers.[11] Moreover, there is often a poor understanding by patients, families, and healthcare providers (HCPs) regarding the potential benefits of transition, which makes the transition process more difficult for them to execute.[12]

VAIs have unique needs, and there is limited information regarding the processes of referral and transition from an ICU to a long-term setting.[10] HCPs are essential to this transition, yet their perspectives on this process regarding barriers and facilitators are not well known. A more detailed understanding of the perspectives of HCPs in this area will inform system improvements to reduce costs further and improve patient quality of life. Therefore, this study's purpose was to better understand the perspectives of HCPs directly involved in caring for adult VAIs in the ICU setting regarding barriers and facilitators to transitioning VAIs to a long-term care setting.

METHODS

STUDY DESIGN

Our methodological approach was qualitative description, as described by Sandelowski.[13,14] Qualitative description supports the development of a comprehensive summary of experiences using commonplace language provided by participants. This approach views participants' words as a vehicle of communication rather than a structure of hidden meanings that require interpretation.[13,14] These characteristics make it a good approach for researchers, HCPs, and policymakers to explore processes and create and revise interventions or programs.[15] We received ethics approval from the Joint West Park Healthcare Centre/Salvation Army Toronto Grace Health Centre Research Ethics Board (September 24, 2019, file # 19-022-WP). All participants provided written informed consent.

SAMPLING AND RECRUITMENT

The sampling frame comprised HCPs in Ontario who typically refer VAIs from an ICU to a long-term setting. Eligible HCPs were those with at least two years of experience managing VAIs in an ICU or step-down setting who have been involved in the referral processes. We purposively recruited HCPs with different roles in the referral and transition process and from different centres across Ontario.[16] We used a snowballing strategy informed by HCPs and researchers involved with transitioning VAIs from ICU to long-term care. Participants were recruited until no new codes were generated.[17]

PROCEDURES

One author (LL) conducted one-on-one semi-structured interviews either in a private meeting room or over the telephone during regular working hours from January to August 2020. Interviews ranged from 30 to 45 minutes in duration. The interviewer had eight years of experience conducting research in clinical settings, was not an HCP (no ICU experience), and did not have a relationship with the participants prior to study recruitment. Open-ended questions invited participants to describe their experience with the processes of referring and transitioning VAIs from intensive to long-term care, including facilitators, barriers, and potential improvements to these processes. (See Supplementary Information for interview guide). Interviews were audio-recorded with participant consent and professionally transcribed verbatim.

ANALYSIS

We used content analysis[13] and a three-step process to analyze data: preparation, organization, and reporting.[18] In the preparation phase, two authors (AMS, LL) immersed themselves in the data, reading the transcripts several times. In the organization phase, an inductive content analysis was performed. The first and second authors independently engaged in open coding and generated categories. These codes and categories were discussed thereafter, and data codes were confirmed. Quotations were selected from the independent coding to verify that the authors coded the data consistently. Categories were then collapsed into higher-order themes using iterative discussion.

RIGOUR

Multiple strategies were used to assess the trustworthiness of the data. The data coding team (AMS, LL) had several meetings, including (RK), a senior regional ventilation coordinator with extensive experience in managing referrals of VAIs from ICUs to long-term care, to discuss the generation of themes. This author triangulated[16] data with his observations and experiences and ensured prolonged engagement was achieved.[16] Methodological coherence[16] was achieved using the qualitative description approach to study design, conduct, analysis, and reporting.

RESULTS

We recruited 10 HCPs with more than ten years of experience working with VAIs in an ICU setting. Participants included social workers, clinical nurse specialists, and specialist physicians (respirologists/intensivists). Most worked in the Greater Toronto Area (GTA) in Ontario. Table 1 summarizes HCP demographics.

In the following sections, we report perspectives on important barriers and facilitators to the transition of VAIs from the ICU to a long-term care setting. Our initial intent

Table 1. Sample characteristics of healthcare providers interviewed.

	Sample (*n*=10)
Profession, *n* (%)	
Respirologist/Intensivist	2 (20%)
Clinical Nurse Specialist	2 (20%)
Social Worker	6 (60%)
Female, *n* (%)	8 (80%)
Work Experience in Long-term Ventilation (years)	10-35
Geography *n*, (%)	
Metropolitan Area/City	8 (80%)
Rural Community	2 (20%)

was to present the process of referral distinctly from the process of transition; however, since HCPs frequently interpreted our questions as pertaining to processes that are inextricably linked, we present the results of referral and transition together. Since our interviews were conducted both before and during the COVID-19 pandemic, we highlight any facilitators and barriers considered specific to COVID-19 protocols.

TRANSITION BARRIERS

Although the process of referral to a long-term care setting was reported as straightforward, participants identified both lack of available discharge locations and access to beds at existing institutions as system-level barriers:

> *And in our whole [healthcare authority], there's nowhere for chronic ventilated patients to go. We apply to the two in Toronto, generally....[that] are the kind of closest places. Sometimes that's not really even that realistic or feasible because our patients' families live out in this area.* (HCP03, Social Worker)

Physicians, in particular, identified the lack of government provision of infrastructure and resources to formally support the transfer of VAIs as a critical system-level barrier:

> *We're not a program because we're not funded as a program...A program is appropriately planned and appropriately funded. And again, you define the necessary roles and responsibilities of the individual so that it's sustained. We don't have all those components... we're expected to be supporting patients over longer periods of time without any centralization of the services. In other words, provincially if I'm looking after a region then there should be appropriate funding to be able to do that from the Ministry of Health. And that hasn't been forthcoming for years.* (HCP009, Respirologist/Intensivist)

Participants viewed the paucity of available discharge locations to be exacerbated by the aging patient population that is living longer and with a greater disease burden. Existing eligibility criteria for acceptance into a long-term ventilation residential placement often precluded complex patients requiring more involved care:

> *There's the people being able to live with chronic conditions longer. There's also the restriction with dialysis, as well, because we have other patients who are chronic vent but they've nowhere to go because they require intermittent hemodialysis which is not offered [at long-term care centres]. So then they stay in the ICU.* (HCP02, Clinical Nurse Specialist)

Participants reported wait times for a bed in a long-term ventilation unit as the most salient and pervasive barrier to patient transition, with evident demoralization due to the frustrations associated with the inability to facilitate transfer. In many cases, patients passed away while waiting for a bed to become available:

> *But anyway, at the end of the day, the wait times are so long, I've never had anybody actually leave to go to one of those places.... So I've done papers for those centres multiple times but even when I'm doing them I know they're never going to get there.* (HCP03, Social Worker)

Participants estimated wait times could be as long as seven years, with concern expressed about the lack of transparency of these wait lists:

> *Our experience has been that the wait lists are not very transparent, in terms of where somebody is on a waitlist and what the anticipated wait is going to be. I find that information has been very challenging to get.* (HCP05, Social Worker)

Lengthy wait times exacerbate the patient's fear of transitioning from the ICU. Participants acknowledged that patients and families take comfort in the ICU environment, with 24-hour monitoring and a familiar clinical team:

> *And I think, just by waiting for years, it creates challenges in the unit. Because they don't need acute care...I think that limits their ability to conceive of life outside of the ICU...And just the fact of going from being on a continuous telemetry monitor to being off the monitor and not being monitored as frequently [is] a very big transition to them. So I'm sure you can imagine, if you've got someone in an ICU for years, who might be hooked up to a monitor but even then, we refer at most, one nurse for two patients. And then going to a less acute environment is a very big, very scary transition that some people might not want to go.* (HCP002, Clinical Nurse Specialist)

Furthermore, VAIs who remain in the ICU as an alternative unit specific to their care needs is not available, experience a sub-optimal transition process:

> *It's not actually the waiting time, it's the fact the patients end up being in almost a stasis situation in which the transition to another location is essentially put on hold. There's no transition process and that's intrinsic because of the priorities in the ICUs. It's very hard to coach teams to move patients and families to a readiness state for transition home or a long-term ventilation unit in an ICU.* (HCP008, Respirologist/Intensivist)

TRANSITION FACILITATORS

Participants reported strong partnerships and trusting relationships between referring and receiving institutions or organizations as aiding referral processes:

> *For me it's the partnership amongst all of the community agencies. That took a long time to build and generate the trust that we weren't just trying to empty an ICU bed for the first community bed...So I think it's the partnership and the trust amongst clinicians.* (HCP06, Clinical Nurse Specialist)

The integral role of community partnerships for facilitation of transfers was especially relevant in more rural locations because their model of care relied heavily on discharge to community partners, as opposed to long-term ventilation units:

> *So our philosophy for a number of years is that we want patients in community...We have a very good partnership with a group and there are assisted living venues of care. It's a venue where there would be 2-4 clients per home. These are homes within suburban areas in the city with disability support workers that we would train so that they're cared for. So there's 24/7 disability support worker care for these individuals. And we have worked with our [healthcare authority] to ensure that there's proper funding, there are proper nurse practitioners that are also linked to the care of those individuals in the community.* (HCP09, Respirologist/Intensivist)

The partnership with community-based respiratory care providers (respiratory therapists) was a critical facilitator in successful patient transition to the community:

> *We have a great community respiratory therapy group and they sit at the table with us as well. And they are willing to maximize their scope of practice, of changing trachs, trouble-shooting ventilation, teaching cough-assist for community partners. Again, make them part of the success, in terms of getting people to the community.* (HCP06, Clinical Nurse Specialist)

While all participants emphasized collaboration between the referring and discharge locations as a transition facilitator, extended collaborative working with the patient and family throughout the process further enhanced the transition. Specifically, in-person familiarization visits attended by staff from both locations fostered trust in the new care environment and promoted concordance with the transition plan:

> *She had the opportunity to go to [long-term care facility] and take a tour and see the facility before her mom went there. Our team went on transport with the patient to the facility. That's something that we do that goes well, helps with the transition. I think it just comes down to lots of communication, lots of information and opportunities for the family to connect with the receiving team, to see the facility. And also to sort of be in agreement with this plan. And to not sort of be in opposition to the plan.* (HCP005, Social Worker)

IMPACT OF COVID-19 ON THE TRANSITION PROCESS

The COVID-19 pandemic was reported to elicit positive change in referral processes. Prior to the pandemic, referring institutions would complete separate applications for each potential discharge location. Once the pandemic began, the regional health authority implemented a centralized referral process, stewarded by the largest long-term ventilation unit in the province. Participants reported this as an important facilitator to streamlining the referral process as it eliminated the requirement for multiple points of contact and greatly improved communication:

> *...the current process, I like the fact that it's all centralized. I don't know if that's going to stay after the pandemic, but we send everything to [central referral facility] and then they kind of distribute to the different facilities, and then we get a call from the facility. So I prefer much doing that as opposed to sending off to 3 or 4 facilities.* (HCP07, Social Worker)

Another participant shared that this centralized referral process "*...has been a wish for 20 years.*" (HCP08, Respirologist/Intensivist)

DISCUSSION

When transitioning VAIs from the ICU to a long-term care setting, participants identified several barriers and facilitators. Chief among the barriers was the lack of discharge locations, limited bed capacity creating long waiting lists, medical complexity of patients, and the lack of waitlist transparency. Key facilitators included trusting relationships between referring and discharge locations, good community partnerships, and a centralized referral system. Participants acknowledged that a prolonged ICU stay fosters dependency and fear of transitioning to another environment. While most transition barriers were system-level, HCPs also acknowledged a provider-level barrier, in better patient and family preparation for transition being helpful to allay fears regarding care at the new location.

This study's findings indicate that many barriers to transitioning VAIs from the ICU to long-term care settings are systemic. Other countries have adopted alternative system-level approaches to manage the care of VAIs. Long-term acute care hospitals (LTACHs) in the United States offer specialized rehabilitation services and dedicated respiratory care for those requiring prolonged ventilation.[19] Although the lower staffing ratios reduce costs of care, it is unclear whether transfer to an LTAC influences survival or health-related quality of life.[20] France's model of care is based on a series of regional networks that emphasize the integration of acute and community-based care.[21] These

regional networks service nearly all VAIs in France and oversee patients transitioning from ICU to centres for Long Term Ventilation (LTV) and to the community, providing support services 24/7 and offering opportunities for the specialized care necessary for the management of VAIs. France's model of care has been shown to reduce costs and improve access.[21] These system-level approaches should be considered in Canadian jurisdictions that aim to improve the care of VAIs.

Unexpectedly, fueled by the urgency of the COVID-19 pandemic to free ICU resources for the surge of critically ill patients, many of the barriers identified by the HCPs regarding the need to transition VAIs have been more promptly addressed than they might have otherwise been. A system-level approach in Ontario has resulted in a rapid allocation of resources to increase bed capacity, with a centralized single queue to provide access to the first available location or service provider.[22] Such systems have been shown to reduce wait lists,[23,24] increase the number of patients seen by healthcare providers,[23,25] and improve access and efficiency of patient care while also improving patient satisfaction in outpatient and surgical settings,[23,26] although detailed evaluation of its impact among the LTV population remains to be reported. Additionally, new community funding for "Family Managed Care" in Ontario has enabled VAIs transitioning to the community to receive additional HCP home support and to recruit their own caregivers rather than being obliged to use an agency. Participating HCPs noted that it also resulted in closer relationships between referring and receiving organizations. It is a scalable approach now being implemented across the province.

While the lack of beds at long-term care centres is a noted pervasive barrier to transitioning VAIs out of ICUs in Ontario and across Canada,[10] this study identified the negative perceived impact on patients and their families as a result of long-waitlist created by the lack of beds. Patients and their families become accustomed to 24-hour care provided by the ICU healthcare team, and rather than perceiving the transition to a long-term care setting as desirable, patients and their families experience fear and hesitation when beds become available at long-term care settings. Improved patient-provider communication, increased knowledge about ICU transition, and an organized learning environment have been identified as ways to improve the transition of VAIs out of acute care.[27] Additionally, many patients and families are burdened by the location of the long-term care centres. Institutional long-term care for VAIs is only available in an urban location, which is not preferred or feasible when VAIs and their families live rurally. According to the 2016 Canadian Census,[28] approximately half of Ontario's population lives in the GTA, indicating that approximately half of the population does not have access to a long-term care facility for VAIs. Timely transfers of VAIs to long-term care settings and an increase in long-term care settings outside of the GTA will ensure that patients are appropriately and equitably supported throughout the province.

While the new system-level approach to increase bed capacity in long-term care settings and support homecare of VAIs in Ontario is promising, leveraging community partnerships may also be important for the optimal care of VAIs, particularly in rural communities. For families who are unable to provide homecare for patients, partnerships with assisted living facilities may provide an avenue that will allow patients to live in the community and closer to their loved ones. While such partnerships will require access to the required medical equipment and staff education, specific centres in Ontario provide a blueprint for scaling this approach across the province.

This study provides important insights into the challenges of transitioning VAIs from acute care. A larger, more diverse sample might have identified additional barriers and facilitators; however, the sampling frame of this population is small. Also, generalizability might be constrained as participants were all within Ontario, not necessarily having the same perspectives and experiences as other jurisdictions. However, the information gained will likely inform the development of new transition programs in a growing area of interest as the healthcare system continues to emphasize the transition from ICU to reduce resource utilization and increase quality of life.

CONCLUSION

Our study presents the perspectives of HCPs familiar with long-term ventilation, who identified key system-level barriers to transitioning from the ICU to long-term care. These include the lack of discharge locations and beds at such locations, creating extremely long waiting lists, and the absence of waitlist transparency. This study is among the first to identify the perceived negative impact on patients and their families stemming from the lack of beds at long-term care facilities and provide potential solutions for addressing this challenge. Pressures on ICU availability associated with the COVID-19 pandemic have resulted in a system-level approach in Ontario with a centralized single cue that facilitates timely access to locations with availability, which might address many of the deficiencies, including wait lists. Future research is needed to assess the success of this change and its impacts on patients and families. The information provided is of value in the design of transition programs for other jurisdictions.

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CONTRIBUTORS

All authors contributed to the design of this work. LL contributed to the acquisition of data. AMS, LL, RK, RG, LR to the analysis of the data. AMS and LL drafted the paper. All authors commented on the draft paper and approved the final version.

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COMPETING INTERESTS

All authors have completed the ICMJE uniform disclosure form and declare no financial relationships with any organizations that might have an interest in the submitting work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

ETHICAL APPROVAL

Informed consent was obtained from all participants. The Joint West Park Healthcare Centre/Salvation Army Toronto Grace Health Centre Research Ethics Board approved this study.

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SUPPLEMENTARY MATERIALS

Supplementary Information

Download: https://cjrt.ca/article/89103-exploring-factors-affecting-the-timely-transition-of-ventilator-assisted-individuals-in-ontario-from-acute-to-long-term-care-perspectives-of-healthca/attachment/184601.docx