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PHI's 9th Research Award: Final Report

Cough Assist: User Education Needs, Health Service Utilization and Outcomes

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Background

Individuals that require ventilator support in the home due to neuromuscular disorders experience frequent chest infections. When severe, this results in emergency department visits and, in some cases, hospital admission.

Cough assist devices that help clear respiratory secretions may help prevent chest infections or lessen their severity. This may help reduce use of healthcare services and associated costs, as well as reducing symptom burden and improving quality of life.

In April 2014, the Ministry of Health and Long-term Care in the province of Ontario, Canada, set up a publicly funded program to provide free-of-charge cough assist devices and associated equipment based on a home ventilation specialist prescription.

Project Aim

Our project was designed to understand the following:

- What education and support is required for cough assist users and their families when newly started and for ongoing use of a cough assist device.
- The impact on publicly funded healthcare services and costs, health-related quality of life and symptom burden.

Methods

We conducted this study in three parts.

In Part 1, we conducted interviews with new (<6 months) and established (6–48 months) cough assist users and family caregivers. We also asked them to rate their confidence using cough assist on a 1 (not confident) to 10 (very confident) rating scale.

In Part 2, we prospectively recruited participants who received a cough assist device through the publicly funded scheme. We then used the Ontario health administrative databases to understand the publicly funded healthcare service use and costs of these participants in the 12 months before using cough assist and in the first 12 months of use.

In Part 3, we assessed health-related quality of life and self-reported breathlessness at three, six and nine months. We also collected a broader understanding of both public and private healthcare costs using participant-reported data as opposed to health administrative databases.

Findings

Part 1: We conducted 28 interviews, including 14 new and 14 established cough assist users and caregivers. Both new and established users were highly confident in use of cough assist, with average scores

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Louise Rose, RN, BN, MN, PhD

of 8.8 and 8.3 respectively. Overall, interview participants were satisfied with their initial education which generally comprised a 1–2 hour one-on-one session at home or in clinic with device demonstration and hands-on practice. They viewed hands-on practice and teaching of caregivers as more beneficial than written materials.

Participants reported ongoing support for cough assist use was variable. Most indicated a lack of specific follow-up resulting in uncertainty if they were using cough assist correctly, or if it was effective.

Things that made interview participants more likely to use cough assist were that it was easy use, the initial training, support from formal/informal caregivers, and that they experienced symptom relief. Barriers to use were inadequate education on why cough assist was needed, technique and benefit, lack of follow-up, and inadequate knowledge of cough assist by community/non-specialist providers.

Part 2: We recruited 106 adults and children using a cough assist device. We found no difference in emergency department visit or hospital admission rates in the 12 months before and 12 months after receiving a cough assist device. However fewer days were spent in hospital (P=0.03). We also found the number of physician specialist visits decreased from seven to four visits on average (P<0.0001). Conversely, the use of homecare nursing and homemaking/personal support visits increased.

We found that the difference in healthcare costs before and after commencing cough assist differed.

"The most important predictor of costs after cough assist approval was the healthcare costs in the 12 months before receiving a device."

For most (59%) participants these were lower, for 13% they were not different, and for 27% they were higher. The most important predictor of costs after cough assist approval was the healthcare costs in the 12 months before receiving a device. At 12 months, 23 (22%) participants had died, with the risk of death highest for those using more medical devices in the home.

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Post-Polio Health International's mission is to collect, preserve and make available research and knowledge to promote the well-being and independence of polio survivors, home ventilator users, their caregivers and families, and to support the health professionals who treat them.

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Part 3: We recruited 108 cough assist users, with most common diagnoses being ALS (40%) and muscular, myopathic and myotonic dystrophies (25%). Daily cough assist device use was 51% of study days on average. We found no change in health-related quality of life overall over the nine-month study duration. The average self-reported breathlessness worsened from a score of 2.1 at baseline to 3.1 at nine months. The average monthly cost of publicly or privately funded healthcare

"Provision of publicly funded cough assist devices did not change the number of emergency department visits or hospital admissions but did reduce the number of days in hospital and specialist doctor visits."

was $1,195 CAD, although costs were substantially higher in some participants. Higher costs were associated with an ALS diagnosis, requiring mechanical ventilation, being non-ambulatory and using the cough assist device on more study days.

Mika Nonoyama, RRT, PhD

Overall Conclusions

Part 1: The current Ontario model of education for the use of cough assist in the home on initiation meets cough assist user and family caregiver needs. Improvements to follow-up education are needed to sustain device benefit and maintain confidence in technique.

Part 2: Provision of publicly funded cough assist devices did not change the number of emergency department visits or hospital admissions but did reduce the number of days in hospital and specialist doctor visits. This resulted in a shift of healthcare utilization and costs from the acute care to community sector. The risk of death was highest in individuals requiring multiple medical technologies in the home that included cough assist.

Part 3: We found no change in health-related quality of life in the first nine months of using a cough assist device but a small worsening in self-perceived breathlessness. Similar to our previous work in home ventilated patients, costs were highest in participants with the greatest disease/symptom severity, including those with ALS, requiring ventilation, non-ambulatory, and also those using cough assist on more study days. ■

Publications to Date

Dale CM, McKim D, Amin R, Carbone S, Fisher T, Goldstein R, Katz S, Gershon A, Leasa D, Nonoyama M, Pizutti R, Tandon A, Rose L. Education Experiences of Adult Subjects and Caregivers for Mechanical Insufflation-Exsufflation at Home. *Respir Care.* 2020 Dec;65(12):1889-1896.

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