**Table 1.** FC Demographic Characteristics

| Demographic | n (%) |
|---|---|
| Gender | |
| Female | 8 (73%) |
| Male | 3 (27%) |
| Relationship to Child | |
| Mother | 8 (73%) |
| Father | 3 (27%) |
| Age range (years) | |
| 30-35 | 4 (36%) |
| 36-40 | 2 (18%) |
| Missing data | 5 (46%) |
| Marital Status | |
| Married or living with partner | 7 (64%) |
| Separated | 1 (11%) |
| Missing data | 3 (27%) |
| Education | |
| Diploma or certificate from trade, technical, vocational school, business college | 1 (11%) |
| Bachelor's, undergraduate degree, teacher's college | 6 (55%) |
| Master's degree | 2 (18%) |
| Missing data | 2 (18%) |
| Household income, range, $CAD | |
| 40,000-49,000 | 1 (11%) |
| 50,000-59,000 | 2 (18%) |
| 60,000- 79,000 | 1 (11%) |
| ≥ 80,000 | 4 (36%) |
| Unsure | 1 (11%) |
| Missing data | 2 (18%) |
| Ethnicity | |
| Caucasian | 2 (18%) |
| South Asian | 3 (27%) |
| West Asian | 1 (11%) |
| South East Asian | 2 (18%) |
| Eastern European | 1 (11%) |
| Missing data | 2 (18%) |
| Number of People living in the Family Home | |
| 3 | 4 (36%) |
| 4 | 3 (27%) |
| 5 | 2 (18%) |
| Missing data | 2 (18%) |
| Number of children living at home | |
| 1 | 7 (64%) |
| 2 | 2 (18%) |
| Missing data | 2 (18%) |

**Table 2**. Child with LTV Demographic Characteristics

| Category | Value |
|---|---|
| Current Age (years) | |
| Median (range) | 3.6 (2.2-12.3) |
| Age Groups | |
| 0-4 | 8 (80%) |
| 5-9 | 1 (10%) |
| 10-14 | 1 (10%) |
| Years since invasive ventilation initiation via tracheostomy (months) Median (SD; range) | 5.7 (39.4; 2.2-130.1) |
| Gender | |
| Female | 3 (30%) |
| Male | 7 (70%) |
| Primary Diagnosis | |
| Musculoskeletal | 3 (30%) |
| Spinal cord injury (SCI) | 3 (30%) |
| Genetic/Metabolic | 3 (30%) |
| Cardiac | 1 (10%) |
| Current Ventilator Support Needs | |
| 24 hour | 2 (20%) |
| Nocturnal | 8 (80%) |
| Median Time Along Pathway (mos) | All participants / Excluding SCI participants^^ |
| Trach to Rehab (SD;range) | 0.9* (0.4;0.3-1.4) / 0.7* (0.4; 0.3-1.4) |
| Rehab to Home (SD;range) | 3.3 (2.7; 1.5-10.1) / 2.2 (1.4; 1.5-5) |
| Trach Insertion to Rehab to Home (SD;range) | 5.1* (2.9;1.9-11.2) / 5.1* (1.6; 1.9-5.5) |
| *Excluding one participant who already had trach/vent | ^^SCI participants typically have a longer rehabilitation course that is not related to LTV needs |
| Median Time in Acute Care (mos) | |
| Admission to Trach (SD;range) | 2.2* (1.3;0.7-4.4) |
| Admission to Transfer (SD;range) | 3.2 (1.5;.2-4.8) |
| *Excluding one participant who already had trach/vent | |

**Table 3.** Recommendations for Hospital to Home LTV discharge pathway

| Recommendation | Corresponding Themes |
|---|---|
| • Improve the decision-making process for FC's by using a family centred care framework that is centred on partnership.<br>• Communication is framed in a realistic way but is grounded in a positive framework regarding the child's prognosis and quality of life and explores child/family life after discharge.<br>• Conversations to be led by HCPs that have experience with the child/family or with children requiring LTV support<br>• Meet LTV team early to address their questions and information needs about tracheostomy and its implications on child/family life.<br>• Designate a HCP as key point of contact for FCs<br>• LTV-specific psychosocial support to be initiated from the start of the process to address emotional distress and carried out throughout the pathway. This may include family to family support. | Making an informed decision |
| • Ensure a consistent and family centred approach to teaching and educational materials across hospital settings.<br>• Appoint a hospital HCP to physically accompany child/family to rehabilitation setting to ensure continuity in care and to act as a process bridge for transition between teams and settings.<br>• Facilitate family participation in all transition meetings.<br>• Engage Social Workers at both sites to prepare for transition and adjustments to new setting and expectations. | Transitioning to rehabilitation |
| • Implement innovative ways to prepare and initiate FC hands on consolidation of their new skills in the intensive care setting.<br>• Expand early learning content to include management of daily life at home along with tending to medical needs of child at home.<br>• Enhanced curriculum emphasis on teaching FCs how to manage acute/emergency situations including more cardiopulmonary resuscitation training. | Building capacity for self-care |
| • Review ongoing respiratory supply costs and provide FCs checklists for maintenance and ordering of supplies<br>• Provide additional information about home supplies (including similarities and differences with hospitals items) as well as the varying options that exist. | Coordinating case management |
| • Extend formal LTV discharge pathway and follow up in the home several weeks post discharge to support continuity of care, in-context problem solving, review of home set ups, checking on equipment/supplies. | Readying for discharge home |

| | |
|---|---|
| • Integrate training of in-home HCPs earlier in LTV discharge pathway and explore tandem training alongside FCs. | Experiencing home care |