

# **VENTILATOR USER'S PERSPECTIVES ON IMPORTANT ELEMENTS OF HEALTH – RELATED QUALITY OF LIFE**

A Canadian Qualitative Study

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**“....don't think of things in terms of barriers... that's part of the problem, you can convince yourself that the wall is really there and it isn't. It's all about what's possible and being good at communication and developing powerful ways of reaching people ...and people do break through what appear to be barriers.” ...Ventilator User**

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## EXECUTIVE SUMMARY

This report outlines the findings of a qualitative study on the perceptions of persons who use various forms of mechanical ventilation about their health-related quality of life (HRQL). The study was funded by a grant from the Gazette International Networking Institute (GINI Foundation) and was conducted in two Canadian cities, Toronto and Edmonton. The study took place over a two-year period: May 2000 to July 2002.

HRQL is a term used to indicate an individual's perception of performance and/or satisfaction in at least one or more of four significant life domains: somatic sensation; physical function; emotional state; and social interaction. This study attempted to investigate all four domains through open-ended interviewing.

The purpose of the study was to expand knowledge of HRQL of ventilator users living in the community. The three primary research objectives were:

1. To examine the concept of HRQL from the perspectives of users of mechanical ventilation at their home setting and to identify what they consider to be its determinants.
2. To explore the relationship between having a significant disability and using home ventilation in terms of their impact on perceptions of HRLQ.
3. To describe how these perceptions evolve over time as individuals living with home ventilation adjust to using the technology and to living independently in the community.

This qualitative study involved interviews with twenty-six Canadian informants who were experienced with using mechanical ventilation at home. The interview instrument was structured to elicit information on all of the areas of HRQL, while allowing interview participants the leeway to bring forward the topics or issues that were highly pertinent to them. Interviews were tape-recorded, transcribed and coded by the research team. Emergent codes and themes were identified and analyzed.

For the purposes of this study, ‘mechanical ventilation’ includes the use of equipment that supports ventilation by means of volume or positive pressure, either invasively (tracheostomy) or non-invasively (masks, nasal pillows, mouthpieces). It also includes phrenic pacers. Participants in the study used these various forms of ventilatory support on a regular basis. No participants were currently using negative pressure modes of ventilation (e.g. cuirass, pneumobelt).

The study revealed that use of mechanical ventilation to support respiratory function is associated with stigma, with assumptions about disability and about what constitutes “normal” healthy lifestyles. Medical practitioners and the general public tend to regard use of mechanical ventilation as an intrusive burden, a form of life support that technologises the body to compensate for pathology. In contrast, for the individuals who participated in interviews, mechanical ventilation is regarded as a form of assistive technology, similar to a wheelchair. It is perceived as a benefit to independent living, enhancing energy and overall health. Interview participants considered themselves to be healthy and to enjoy a high quality of life, thus countering societal assumptions about use of mechanical ventilation and disability.

**“My energy was back, I was renewed, I was in wonderful... it was just, it was noisy because the air had to escape, it went kshhhhh every breath, but that didn't bother me because I was so glad to have this wonderful thing that was making me breathe.”**

**“I discovered it just gave me so much more energy to work throughout the day. I figured what the heck, you know, why struggle when I don't have to.”**

While participants' perceptions of the use of mechanical ventilation were primarily positive, several areas of dissatisfaction associated with the technology were identified. Some participants found the size of their mechanical ventilation equipment cumbersome, especially for travelling out of the house; some participants found that the equipment was noisy, especially at night. Another area of concern for some participants centered around suctioning. Some participants found that their need for suctioning interfered with their independence because they did not have adequate and appropriate support persons to accompany them out of the house. Suctioning equipment was also regarded as cumbersome by some participants and therefore, a further barrier to getting out of the house.

**“The main change I find is that I can't spontaneously go out like I used to... now I can go more now than (when) I first got it (the trache)... I couldn't go anywhere without somebody accompanying me in case I needed suctioning and, for a long time after I got back home, I wouldn't go out, even out of the building for a little while, and then I decided, I said to myself you're so long between suctionings in your apartment, try going outside and you can get back in again before long and gradually I extended my (trips) around the block...”**

We asked participants what they felt would be required to improve their quality of life and their satisfaction with life. They generated many innovative suggestions, which are summarized below.



- Continue support for or expand mechanical ventilation equipment services – offer more flexibility to consumers in terms of equipment choice.
- Increase support for personal support workers/attendant services – structured for the convenience of users rather than providers.
- Improve funding and co-ordination of the healthcare system and services.
- Increase accessibility to public buildings, services, recreation opportunities and travel.
- Design more convenient mechanical ventilation technology, quieter and smaller ventilators – based on input from users.
- Provide public education on mechanical ventilation/respiratory issues – promote respect for persons who have disabilities.
- Incorporate information/training about home use of mechanical ventilation into education of healthcare practitioners.
- Reduce the bureaucracy in social services – provide appropriate services in a timely manner.

In summary, this study investigated the lived experiences of users of mechanical ventilation and expanded the knowledge on how to improve quality of life for users of mechanical ventilation. The results of this study will be disseminated both among consumers and health care providers.

### BACKGROUND AND LITERATURE

Patients with chronic ventilatory inadequacy due to neuromuscular disease may require mechanical ventilation outside the traditional environment of the hospital (1). Home mechanical ventilation has been defined as “the longer term application of ventilatory support to patients who are no longer in acute respiratory failure and do not need the sophistication of an intensive care setting” (2). A task force of the American College of Chest Physicians identified the goals of long term mechanical ventilation as increasing longevity, decreasing morbidity, enhancing quality of life, and maximizing cost effectiveness (3).

Long term home mechanical ventilation was first used during the polio epidemic in the 1940s when the iron lung was applied to improve survival (2). More recently, interest in home mechanical ventilation has increased dramatically due to advances in technology, better home services and a desire to enhance the allocation of health care resources and maximize psychological benefits to families and patients (2). In a cross sectional study, Adams and colleagues (4) reported a 110% increase in the number of patients who are mechanically ventilated at home or in a long-term facility over a six-year period. Canadian data from Litwin and colleagues (5) revealed a 21% increase in home ventilation during their one year of study.

Management with home ventilation varies widely, being a life support system for patients without respiratory independence (e.g., high cervical spinal cord injury, end stage neuromuscular disease) or elective therapy for patients with progressive chronic ventilatory insufficiency (e.g., muscular dystrophy). Use of home ventilation may be

continuous or intermittent, with either a tracheostomy, or a face or nasal mask, or with negative pressure ventilation.

Several retrospective studies have examined survival and long-term outcomes of home mechanical ventilation in patients with neuromuscular disease (6-10). A large variation in survival rates among home ventilated patients has been reported and may be a function of a number of factors such as the effect of tracheostomy, the type of disorder, severity of the illness, type of ventilation and advances in ventilator technology. For example, three-year survival in invasively ventilated patients with severe restrictive pulmonary disorder was 74% for patients without spinal cord injury and 63% for those with spinal cord injury (6). In contrast, patients with neuromuscular disease receiving non-invasive ventilation at home had a two-year survival of 90% (10), and five and ten year survival rates of 76% and 61% respectively (7).

Health-related quality of life is a term used to refer to a “patient’s perception of performance in at least one of four important domains: somatic sensation, physical function, emotional state and social interaction” (11, 12). The term “health-related” is used to exclude certain aspects of life that may be distant from health such as freedom and quality of the environment (11, 12). Measures of health-related quality of life provide insight into the impact of a chronic disease on a patient and may not correlate with physiological measures (11, 12). There are two main types of instruments to measure health-related quality of life: generic instruments that apply to a variety of populations but may be unresponsive to changes in specific conditions; and specific instruments which are developed in a specific population and may therefore be more responsive to change (11, 12).

We could not locate any specific instruments that have been validated to measure health-related quality of life in home-mechanically ventilated patients with neuromuscular disease. However, several researchers have attempted to measure life-satisfaction and health-related quality of life in long-term ventilated patients with neuromuscular disease (13-18), using either generic tools (e.g., Sickness Impact Profile [14]), or standard psychological instruments (e.g., Campbell's Scale of Life Domain Satisfaction Measures, [15]).

Goldstein and colleagues (19) reported on user perspectives among a diverse group of individuals receiving home mechanical ventilation (19). This information was derived largely from an open-ended interviewer administered questionnaire. The questionnaire focused on the user's perceptions of the impact of home mechanical ventilation on their lives and their satisfaction with the decision to initiate ventilation. The results showed that ventilator users' adapted well to ongoing ventilatory support recognized the positive impact on their lives and would choose ventilation again if they were asked.

This study extends these observations by expanding the knowledge of HRQL of ventilator users living in the community.

## RATIONALE FOR THE STUDY

Most research on ventilator users has been medically focused, designed by and driven from the perspectives of health care practitioners, or has been preliminary in nature, and therefore lacking insight into the lived experience of MV users. This study was designed to investigate those lived experiences.

The three primary research objectives were:

1. To examine the concept of HRQL from the perspectives of users of mechanical ventilation (MV) at home and to identify what they consider to be its determinants.
2. To explore the relationship between having a significant disability and using home ventilation in terms of its impact on perceptions of HRLQ.
3. To describe how these perceptions evolve over time as individuals living with home ventilation adjust to using the technology and to living independently in the community.

This study attempted to investigate all domains of HRQL through open-ended interviewing. The interview instrument (Appendix 1) was structured to elicit information on all of these areas, while allowing interview participants the opportunity to bring forward topics or issues that were highly pertinent to them. That this strategy was successful is indicated by the nature of the data we received; we found many interesting and unanticipated issues emerging and at the same time collected important information on the issues we set out to explore.

This study is qualitative in its design. Qualitative, participatory research has been identified as highly suitable for disability-related topics, in that it shifts the focus from regarding research participants as objects of study to regarding them as active subjects

who are engaged in producing the knowledge that is generated. Collaboration between researchers, clinicians and consumers provides a vehicle for investigations that, through their exclusivity, are able to capture perspectives that may not be elicited by quantitative research methodologies. As a qualitative study, it is intended to enrich the knowledge base on home ventilation by giving a voice to individuals who use it.

## METHODS

This qualitative study involved interviews with twenty-six Canadian informants who were experienced with using MV at home. A review of the literature on use of mechanical ventilation was undertaken during development of the research proposal. The literature review informed the development of the interview questions and criteria for inclusion of interview participants.

### 4.1.0 Inclusion Criteria

Inclusion criteria for the study were structured to allow us to capture the experiences of MV users who a minimum of several years of experience using the technology at home.

The inclusion criteria were:

- ❑ 21-75 years of age (originally 25-75)
- ❑ at least two years' experience using MV (originally five years)
- ❑ male/female balance
- ❑ wheelchair users
- ❑ using MV on an everyday basis, minimum requirement of nocturnal use
- ❑ living in the community or in an institution
- ❑ adequate English language skills to participate in an interview (We accommodated needs for communication augmentation)

We limited the range of medical conditions that required the use of MV to those that are related to neuromuscular disease, disorder or injury.

*Included conditions were:*

- ❑ Spinal Muscular Atrophy (SMA)
- ❑ Neuropathy
- ❑ Amyotrophic Lateral Sclerosis (ALS)
- ❑ Dystrophy
- ❑ Duchenne Muscular Dystrophy (DMD)
- ❑ Post Polio
- ❑ Myopathy
- ❑ Cervical Lesion or Spinal Cord Injury (SCI)

*Excluded conditions were:*

- ❑ Chronic Obstructive Pulmonary Disease (COPD)
- ❑ Kyphoscoliosis

We required participants to be non-ambulatory users of wheelchairs, in order to ensure that support with activities of daily living was required. We felt that this was important in order to determine how the additional and unique assistance that ventilation use requires might further affect perceptions of quality of life.

## 4.2.0 Data Collection

The study utilized an open-ended interviewing format. Questions for interviews were developed by the research team based on the literature on home ventilation as well as the expertise possessed by members of the team. The interview instrument went through several iterations in its development, was piloted with two informants and then revised a final time (see Appendix 1). The team included an experienced interviewer who performed all of the interviewing. Potential interview participants were recruited in the Greater Toronto Area (GTA) through disability advocacy groups such as



Citizens for Independence in Living and Breathing and The Centre for Independent Living, Toronto), through West Park Healthcare Centre and through word of mouth. Initial recruitment occurred in the Greater Toronto Area (GTA) in the province of Ontario, Canada. In the latter stages, recruitment was expanded to include Edmonton, Alberta, due to the presence of a significant population of polio survivors. The Respiratory Home Care program that provides equipment and support to MV users in the Edmonton area assisted with recruitment.

Individuals who indicated an interest in being interviewed were contacted by the team's interviewer, who screened them for the inclusion criteria and explained what the study involved. Eligible candidates were sent a package that provided further information about the study and a consent form (Appendix 2). Interviews took place primarily in participants' homes. The interview involved completion of a demographics form (Appendix 3) as well as a series of questions that were designed to elicit open-ended responses. Interviews typically lasted from one to two hours. They were tape-recorded (with participants' consent) and the tapes were then transcribed. Interview participants were given a \$50.00 honorarium in recognition of their investment of time to participate. Participants will also receive a copy of this report.

As transcriptions of the interviews were completed, they were circulated to the research team members. Monthly meetings were held to discuss the transcripts and the issues emerging from them. Saturation of the issues contained in the data was monitored in order to determine when an adequate number of interviews had been completed.

### 4.3.0 Data Analysis

Coding of the transcripts was initiated after the first five interviews had been transcribed and reviewed by the team members. The project coordinator utilized a qualitative data analysis program (NUD\*IST) to code the transcripts. The coding system was developed collaboratively by the team. In order to validate the coordinator's coding, team members coded some transcripts independently and the codings were then crosschecked for consistency. Eleven primary coding categories were developed, as displayed along the left side of Table 1. The eleven primary coding categories were cross-referenced to the demographic categories displayed across the top of Table 1 in order to allow for identification of demographic differences in experience.

4.4.0 Table 1: Coding Framework

	Male	Female	Age = Under 25	Age = 25 - 35	Age = 36 - 55	Age = Over 55	Critical Intro	Non- Critical Intro	Trache	No Trache
Introduction to MV										
Adjustment to MV										
Daily Life										
Facilitators for Daily Life										
Barriers in Daily Life										
Satisfaction in Daily Life										
Dissatisfaction in Daily Life										
What is Needed to Improve Daily Life										
MV or Disability as a Factor Affecting Quality of Daily Life										
Advice for Consumers Considering Using MV										
Advice for Providers										

For the eleven primary coding categories, transcripts were sorted by gender, age, whether participants' introduction to MV was related to a critical or non-critical health situation, and whether participants were ventilated invasively or not. Of these demographic categories, gender and age did not appear to influence perspectives on quality of life when using MV, but the nature of the introduction (critical or non-critical) and the presence or absence of a tracheotomy did produce differences.

In addition, the following issue-specific sub-categories emerged:

- Transportation
- Personal Support Workers
- Funding for MV Equipment
- Health Care Experiences
- Advocacy

Reports on the eleven primary and five secondary coding categories were generated, reviewed, analyzed and synthesized by team members. A brief preliminary summary of the key findings was developed and circulated to participants along with a questionnaire soliciting feedback (Appendix 4). Participants who lived in the Greater Toronto Area were also invited to attend a feedback session in which more detailed information about the data was presented and discussed.

The questionnaires and the feedback session confirmed that our analysis of the issues was consistent with participants' experiences and perspectives, as well as providing further information that expanded on some of the issues.

### 4.5.0 Limitations

The participants who were recruited for this study may not be representative of the overall population of home MV users due to some recruitment bias in our methods and the size of our sample. Because we recruited primarily through networking consumer groups, we tended to make contact with individuals who were connected to the community and/or were involved in advocacy. For the most part, our interview participants tended to be highly successful, active individuals who had adjusted to home MV use, accommodated it into their daily routines and moved forward with their lives. They were almost universally positive about using MV, although they had concerns about the technology itself in terms of convenience. They regarded themselves as healthy, active individuals living fulfilling lives.

Thus, while the voices of MV users who may be having less positive experiences are generally not represented here, this study does portray the “up” side of home mechanical ventilation, thereby providing important evidence which counteracts the commonly held belief that individuals “on a ventilator” have a poor and unsatisfactory quality of life.

## PARTICIPANT DEMOGRAPHICS

Twenty-eight interviews were undertaken for this study, of which two were pilot interviews. Of these, two interviews were excluded from data analysis because, after the interviews began, it became evident that these participants did not meet the criteria for inclusion in the study (they were ambulatory). The final group of participants numbered twenty-six, which included the pilot interviews. The pilot interviews displayed little difference from the quality of the other interviews and contained what we considered to be valuable data. Nineteen interviews were conducted in the Greater Toronto Area and seven in the Edmonton area. Specifics of the demographic profiles of interview participants are presented in Appendix 4. Basic demographics are displayed in Table 2.

**5.1.0 Table 2: Basic Demographics**

<b>BASIC DEMOGRAPHICS</b>	
<b>GENDER</b>	
MALE	16 (62%)
FEMALE	10 (38%)
<b>AGE</b>	
UNDER 25	5
25 – 55	14
OVER 55	7
AVERAGE AGE	44
AGE RANGE	23 – 66
<b>CONDITIONS REPORTED BY PARTICIPANTS</b>	
POLIO	7
MUSCULAR DYSTROPHY	6
SPINAL MUSCULAR ATROPHY	6
SPINAL CORD INJURY	4
CEREBRAL PALSY	1
ALS	1
TRANS MYELITIS	1
<b>TYPES OF MV EQUIPMENT USED</b>	
PIV-100	9
LP-6	7
BI-PAP	3
LP-10	3
Phrenic Pacers	2
LP-20	1
Companion 2801	1

Males are over-represented in this study due to the availability of individuals who both met the inclusion criteria and were interested in participating. Although we strove to achieve a balance between male and female participation, our recruiting efforts produced more male than female participants.

Participants were asked to identify any racial or ethnic community with which they self-identified. Only three reported an affiliation. Most participants were engaged in either paid or volunteer employment. Some owned their own businesses or were homemakers; others were caring for other family members. One participant was living in a rehabilitation hospital, the rest were living in the community in Supported Living Units (6) or with family members. All but two participants required assistance with activities of daily living, which were provided by Supported Living Unit staff, home care, self-managed attendants and/or family members.

During the interviews, participants were asked to rate their perception of their health on a scale of 1 to 10, '1' representing the lowest health status and '10' the highest. Participants were generally very positive about their health. The average reported was 7.5 out of 10. The lowest score was 4 and the highest was 12 (which were off our scale!).

**KEY FINDINGS – “*What Participants Told Us*”**

Discussion of the data has been organized according to the coding categories that were developed. Participants brought forth the same issues many times when responding to the questions presented (Appendix 1), and for this reason themes and issues frequently reappear under the different coding categories, i.e.

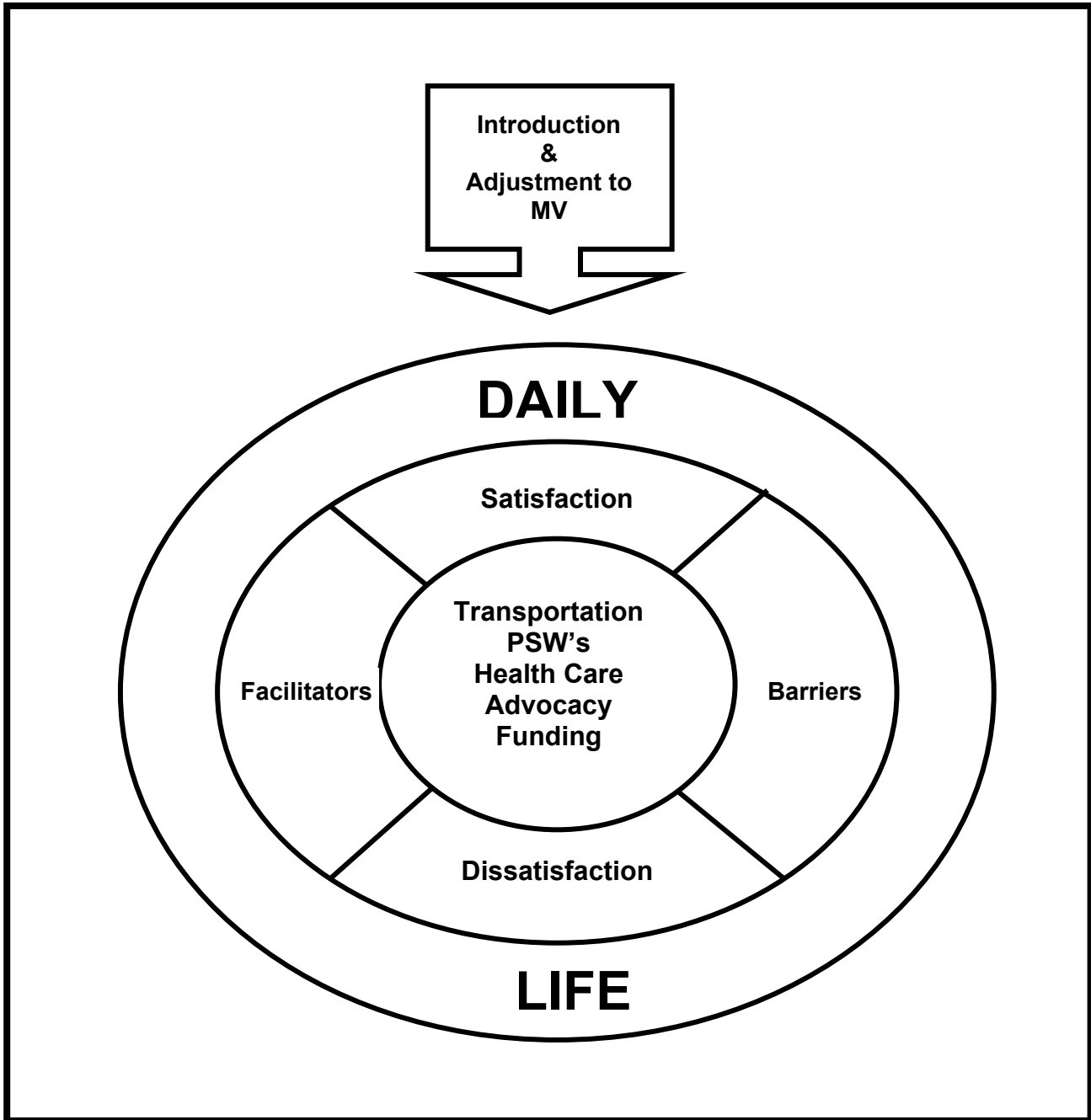
- Facilitators of Daily Life
- Satisfaction with Daily Life
- Barriers in Daily Life
- Dissatisfaction with Daily Life
- What is Needed to Improve Daily Life
- Advice to Consumers, Advice to Providers

The five issue specific sub-categories which emerged during the interviews are presented and discussed within the preceding primary categories on which the interview questions were based:

- Transportation
- Personal Support Workers
- MV Equipment
- Health Care
- Advocacy



6.1.0 FIGURE 1: Relationships between Coding Categories



## 6.2.0 Introduction to MV

### 6.2.1 *Reasons for MV*

Participants in this study presented a broad range of diverse experiences in terms of their introduction to mechanical ventilation and the reasons for that introduction. Some were survivors of polio and had been using ventilatory support for decades, starting with the iron lung and moving on to new technologies as they were developed. Some made decisions to use MV to remedy health-related problems such as sleep apnea, headaches or low energy, and thereby improve their day-to-day lives and health.

**“What I was finding was that I couldn't stay awake in meetings and occasionally I would just be moving along in a mall or something like that and end up with my chair up against a wall or in the middle of a rack of men's suits or something. I had fallen asleep... I can remember a couple of times waking up in (the) middle of a conversation, the person saying ‘what happened?’ because I had actually fallen asleep talking to somebody.”**

**“I went to my general practitioner who was excellent and told him I was waking up all the time at night and that I wasn't getting enough sleep because I kept waking up and kept having the same recurring dreams that I was drowning and I'd be just under the water and then I would wake up and I'd be gasping and he decided I was having psychological problems and sent me to a psychiatrist. The psychiatrist went through whatever form they go through to determine depression and he told me I was not depressed and my sleeping problems weren't caused by emotional distress... Went back to the GP and he referred me to the polio clinic and from there I went to a sleep study and it was diagnosed as a breathing problem.”**

### 6.2.2 *Planned vs. Emergency Introduction*

For some participants, ventilation was introduced under emergency conditions, for example as a result of a pulmonary exacerbation or sudden traumatic event. In the emergency situations, mechanical ventilation was required for sustaining life. In these cases initial acceptance of the technology appeared to proceed without significant problems. Although these participants accepted the need for ventilation, some expressed a desire to have had more control over the decisions around the type and invasiveness of the technology.

It is often assumed that introduction to MV is more difficult when it occurs suddenly, without preparation, under critical care situations. However, critically introduced MV participants in this study appear to have adjusted just as well as those who were introduced to MV under non-critical circumstances. This outcome may be related to the fact that participants who had time to make a decision about initiating long term MV also faced difficult challenges related to working through the decision-making process.

Participants who chose to use MV under non-emergency conditions presented more varied experiences. Some participants appeared to have made a fairly early straightforward decision to try the technology.

**“I’m really glad I went for it when he said it could be the beginning of the end. At the time I told him if I could just sit and read a book and be more comfortable breathing that’s better than I feel now”.**

### 6.2.3 Practitioner Beliefs and Practices

Others felt that they had been discouraged from trying MV by health practitioners who presented it as a form of life support that would produce life-long dependency.

**“The machine symbolized the fact that hey, you're on life support, and um, you are going to die, you know. If you don't do this, you're going to...”**

This reluctance to introduce MV appeared to generate concerns on the part of some participants that initiation of MV would hasten or increase their dependence on MV. In some cases, this resulted in deferral of MV introduction or a conscious effort to use it as little as possible.

**“I try to stay off the ventilator unless I really, really need to be on it because I don't want my body to get used to not breathing by itself because I don't want to have to end up using the ventilator all the time.”**

Overall, practitioner attitudes toward MV appeared to have a significant influence on consumer attitudes. Participants who had positive practitioners and received good support tended to have positive introductory experiences.

**“The doctor was pretty good, he knew because at the beginning he told me, he called us into a room, he says I'm going to do the best I can, but I'm not sure if he's going to make it. And I said, please, do what you can. And he says, I'm going to try, and he was just, from the beginning, he was great.”**

**“They were very very great, I mean they're amazing, they were good. Some people complained but we had the best care. The nurses, everybody, it was just fabulous. Thank God, it makes things easier.”**

#### 6.2.4 Education about MV

Some participants felt that they had received little information about MV and the range of options and benefits it offered, and therefore had difficulty making informed choices.

**“I didn't know what to expect or what questions to even ask.”**

**“I talked to my respirologist and a couple of people I knew with ventilators but I didn't know what to ask so I didn't learn as much as I could.”**

One participant expressed the opinion that if he'd known about the positive health benefits to be realized, he would have initiated MV years earlier.

**“...It (the ventilator) made me very happy, because it made me comfortable and...I wish I'd started long before I did and I could have avoided getting sick so much.”**

Other participants felt that they had been well supported for MV introduction, receiving adequate information about their options and appropriate training in the use of equipment. Some were exposed to individuals who were already successfully using MV and this was considered to be a positive influence.

**“Oh, ya, I remember at the time they showed me a video at the hospital about this woman who had been on a ventilator from polio also, and I think at that time she was 12 years, 15 years on a ventilator. How could she do that? How is that possible? You know, at that time I just couldn't see myself living on a ventilator, with a ventilator, and she was on it 24-hours. And 12 years have gone by and it doesn't seem that long.”**

### 6.2.5 *Psychological Trauma*

Psychological trauma was associated with the introduction of MV for a number of participants. For some, a critical health incident associated with an extended stay in an intensive care unit was the source of this trauma. Among these, a few participants had the impression that life-and-death decisions were being made on their behalf by health care providers who felt that they should be allowed to die because their quality of life would be seriously compromised. In some of these cases, assertive advocacy on the part of family members resulted in ventilatory interventions. Some were left with the feeling that, as far as the medical profession was concerned, they were not worth keeping alive.

**“The specialists saw the x-rays, said nothing was really wrong and sent us home. They made me an appointment for a month later for a sleep study. If I waited a month I would have died. We ended up the same night going to the hospital again. When other doctors saw those x-rays they said “what kind of doctor looked at them?” they were so surprised. There was a black shadow on one side. They could see there was pneumonia.”**

### 6.2.6 *Loss of Previous Lifestyle*

Other participants associated the introduction of MV with loss of employment or with a life change that happened at the same time as (although not necessarily as a result of) introduction of MV. A third factor that contributed to experiences of psychological trauma was the “loss of voice” associated with introduction of a tracheotomy. Being deprived of verbal communication during a time of health crisis and

psychological trauma was frustrating and contributed to feelings of helplessness and loss of control.

**“...You're trying to tell them what's wrong ... Oh, it was difficult. I'll tell you that no communication, boy that is the worst thing that could happen.”**

**“The doctor that put my trache in, well,.....they couldn't figure out why I couldn't talk. Every now and then I might be able to speak.. get a word out... but I couldn't say a sentence of any kind, and he couldn't figure out what was going on and I was in there like, I guess about three weeks and he came in and he said, I'm going to try one more thing with you. He always thought that I wasn't trying. Now telling me I wasn't trying, because I'd try anything, right, and so he came in and said he'd try one last thing and he went out ... I had a size 8 trache in and he put in a size 6 and the minute he put it in, I spoke. I talked... and he looked at me and said, Oh my God, I'm so glad I figured this one out.”**

### **6.2.7 Provincial Differences**

Based on the interviews conducted in Toronto and Edmonton, there appeared to be differences in philosophy between the two provinces in the study, Ontario and Alberta, about when and how to introduce MV. The information provided by participants in the study suggested a tendency in Ontario to delay the introduction of MV when it is considered to be voluntary, and a greater tendency to use invasive technology (tracheotomy) when MV becomes critical to survival. In Alberta there appeared to be earlier introduction to MV, using less invasive technologies. This could be related to the differing histories in the two provinces. Alberta experienced more severe polio

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epidemics while Ontario’s experience with polio was less widespread. As a result, the participants in Alberta were primarily respiratory polio survivors who had moved through a variety of non-invasive MV technologies over the years as they became increasingly available. (In some cases these ventilator users helped develop new technology, such as a mouthpiece). Ontario’s experience with long term home MV appears to be more recent and to have developed from a broader range of medical conditions which may have required more acute or emergency introductions.

### **6.3.0 Adjustment to MV**

Adjustment to using MV obviously starts as soon as MV technology is introduced. Although adjustment is both physically and emotionally demanding during the initial weeks, months and years of MV dependence, adjustment and acceptance do occur over time as MV users get used to MV technology, as overall health improves, and as daily lives and routines become established.

There are three phases to this adjustment, although obviously emergency introduction may not have involved any decision-making phase:

- (1) Deciding to start using MV
- (2) Introduction to MV
- (3) On-going adaptation and learning about life with MV

Factors were identified that facilitated or impeded participants’ adjustment to home use of MV. In some instances, interview data has been coded to both Introduction to MV and Adjustment to MV because there is no clear distinction between these two phases. (In retrospect, it would have been interesting to have asked participants what



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they considered to be the transition point between introduction and long-term adjustment.)

### 6.3.1 *Time and Experience*

Adjustment to the use of MV appeared to be influenced most significantly by individual differences and strategies. Most participants found that it took time, and experience with using MV equipment. The learning curve associated with gaining the expertise and confidence required to manage positive pressure ventilation, as well as proper operation of the equipment was significant, but most participants were proactive about these challenges.

**"... I have more things to do, I have to wash the vent, the tubes from the vent, clean them. You know, you have to watch more... We have to order supplies - suctioning catheters, gauze and stuff, always. You have to keep track of everything... But we're managing fairly well. I thought, Oh my God, how my going to do this? It's too many things... And how am I going to learn this?, but now I just do it like a piece of cake, like it gets into your everyday routine and it's easier."**

### 6.3.2 *Improved Health*

Over time, all but one participant became comfortable with using MV and felt positive about its benefits. A majority of participants commented on the overall improvement to quality of life they had experienced as a result.

**"My energy was back, I was renewed, It was wonderful... it was just, ... it was noisy because the air had to escape, it went kshhhhh with every breath, but that didn't bother me because I was so glad to have this wonderful thing that was making me breathe."**

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**“I discovered it just gave me so much more energy to work throughout the day I figured what the heck, you know, why struggle when I don't have to.”**

The benefits associated with use of MV appeared to assist with the adjustment process as participants found that their overall health and energy improved and the occurrence of health problems such as respiratory infections and headaches decreased, resulting in fewer admissions to hospital for conditions such as pneumonia.

Some also found that they were able to reduce their reliance on MV equipment over time as their health status improved due to improved respiratory intake.

**“Yes, my body has a better O<sub>2</sub>/CO<sub>2</sub> balance which has translated into a more stable standard of life. When I first started using a vent, I was on it 24 hours/day but now only about 10 hours/day which gives me more independence to lead a somewhat normal life.”**

Improvements to energy, to ability to concentrate and to get out of the house also facilitated greater opportunities for employment, education and volunteering activities.

Several participants who had deferred introduction of MV and then had to have emergency intervention during a critical health episode felt that an earlier introduction would have made adjustment easier. They believed that an earlier introduction would have offset some of the declines in health they had experienced in the years leading up to use of MV, and would have prevented the crisis that eventually made MV introduction of MV mandatory for survival. They also felt that they might have been able to have a less invasive form of MV (i.e. avoided having a tracheotomy) if they had started earlier.

### 6.3.3 *Taking Control*

Some participants, perhaps because of concern about MV overdependence and allowing breathing muscles to weaken faster or the need to be free of MV as much as possible, took control of how frequently, they used MV. For example, they slowly weaned themselves off 24-hour dependence on MV, tried different kinds of equipment and learned new techniques such as Glossopharyngeal Breathing (frog breathing).

**“I was supposed to die, I was very sick..... It took a good three-and-a-half years after being trached to wean myself off during the day and I learned how to suction myself, I learned how to change my trach and it took a good three-and-a-half years.”**

**“I think over the first maybe two years, being ventilated with a mechanical ventilator was certainly one step, weaning and getting away from a lot of suctioning was maybe the second step, moving to rehab and learning how to (frog) breathe would certainly have been another step so things have changed a lot and now we're getting to the final step, getting rid of my trache.”**

### 6.3.4 *Suctioning Issues*

The need for suctioning (related to the presence of a tracheotomy) emerged as a challenging and significant adjustment issue for those consumers affected by this problem. A few participants had minimal requirements for suctioning, or were able to suction themselves, and did not identify suctioning as an issue. However, the majority of participants with tracheotomies required assistance with suctioning, and/or required suctioning on a regular or frequent basis.

**“...when I began to get stronger I began to think "well, what is the difference really in my care now to what it was before the ventilator**

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and then I would think and reason out in my head the difference... it's something that people could learn, it's not a difficult thing to learn how to do it and I figured the hardest part for the staff ...would be the suctioning. Putting myself in their shoes, I would feel suctioning somebody would be the most nerve wracking part... putting something down somebody's throat... I began to realize it's something they could be taught."

### 6.3.5 *MV Technology*

Adjustment to life with ventilation appeared to be facilitated by the fact that most participants were already used to using other adaptive equipment, such as wheelchairs. They seemed to accept their MV equipment as just another piece of technology that supported their health and independence rather than perceiving it as “life support” per se.

Some participants had moved through various types of equipment as time progressed, due to the changing requirements of their conditions and improvements in technology. (For example, polio survivors commonly started with the iron lung, moved on to the cuirass and/or rocking bed, and then went on to positive pressure support.) Long-term users experienced a gradual improvement in the range of technology that was available and benefited from the increased independence that they could enjoy as a result – for example, the smaller size and greater portability of the ventilator enabled participants to move out of hospital and into community life.

While use of MV was generally considered to have contributed to improvements in quality of life and independence, aspects of the technology itself were considered to be an impediment to adjustment. The bulk, size and intrusiveness of suctioning and

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ventilator equipment and the noise produced, particularly at night and especially when sleeping with a partner, were cited as disadvantages.

Limitations on individual choice of equipment provided through government programs were also an issue. For example, smaller, quieter ventilators and more efficient suctioning machines may not be available through government-funded programs, even though they are on the market. Participants who voiced these concerns felt that their ongoing adjustment would be facilitated by consumer input into the design and development of improved MV technologies and greater industry responsiveness to their preferences as well as choice.

The size, noise, function and weight of MV and suctioning equipment imposed challenges to mobility and the freedom to travel, and hence impacted on adjustment to life with MV.

**“I hate dragging this thing (the ventilator) around. But that’s a fact of life. I understand there’s a new, smaller one out that you can tuck in your backpack so that would be nice for traveling around.”**

Participants described difficulties which ranged from inability to get into someone’s house because of the size of the ventilator on the back of the chair to difficulties when traveling away from home, either over-night or for extended travel periods.

**“...It’s really hard... gotta bring a lotta stuff ...like you go for one night, two nights & you’re looking at a week or two of stuff and it’s just crazy. It’s too much work.”**

**“ Well, there’s a lot of stuff you have to bring. You’re looking at a ventilator, ...humidifier,...water,...suction catheters,...stuff to clean your trache,...you need to bring extra stuff if something breaks,...it’s the whole nine yards you gotta bring!”**

Participants experienced difficulties finding room for their equipment in vehicles, and in taking it onto airplanes (where they also faced attitudinal barriers in accommodating the need to have the equipment nearby). Some participants had devised ingenious strategies to overcome these problems, such as disguising the equipment when boarding an airplane or purchasing smaller equipment for travel purposes from their own financial resources.

Other, longer-term ventilator users, whose original large negative pressure equipment had been replaced over time by modern smaller units, felt that their adjustment to MV had been vastly improved by the opportunities to travel that such changes in MV technology had afforded.

**“So there's no question that the mouthpiece combined with smaller ventilator development made a huge difference in the ease of traveling. It didn't stop me from traveling before, but it was more difficult.”**

### **6.3.6 Having Choices**

Opportunities for trying and selecting different MV equipment and interfaces so as to arrive at the most satisfactory, least problematic, personal solution was a factor in positive adjustment to MV. Having choices, trying different modes of ventilation or interfaces and deciding on specific MV products enabled participants to take control of their situation.

Some participants could not tolerate having a mask on their faces for various reasons or just preferred other modes of air intake. One participant, who could no longer use a cuirass or accept a tracheotomy again, worked with his dentist to develop

an oral mouthpiece that proved to be an acceptable and viable alternative. Others actively investigated different types of MV over time, such as phrenic pacers, and eventually chose to have phrenic pacers implanted and their tracheotomies closed.

Some participants who had been ventilated invasively spoke positively about the benefits of having a tracheotomy while others found it uncomfortable and difficult to maintain, often because of the extra work, need for suctioning and personal support requirements associated with it.

In some cases, provider advice was kept in perspective or even disregarded as participants became more experienced with and confident about using MV over time.

### **6.3.7 Stigma and Acceptance**

Some participants initially felt embarrassed and stigmatized by the visibility of their equipment or tracheotomy. Lacking knowledge or experience, and being influenced by common public and media perceptions that MV is an “ICU life-supported” phenomenon, it was difficult for them to believe they had any kind of quality of life ahead of them.

For some, introduction of MV coincided with termination of employment. They felt that their dependence on MV technology had seriously inhibited their previous quality of life, at least in the early years, if not on an ongoing basis. One participant, who could now no longer work, remained distressed about having been placed on MV during a critical health incident some years earlier, and appeared to have never truly adjusted to its use.

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MV users who had a difficult initial adjustment took quite a while before they could talk about it, take their MV equipment out in public or even be seen using it. For some, this embarrassment has continued.

**“It was a long time before I would go out of the street with it on my chair or use it in public.”**

**“I would love to have the nerve to take it (the ventilator) to the theatre for a four-hour performance instead of ducking out at intermission and going to the car and taking a 15-minute air break and going back in...”**

**“I still get embarrassed once in a while... if there's a hose loose or something and it starts alarming... like in a movie theater or in the middle of the church sermon... everybody turns around.”**

For these individuals initial adjustment was psychologically difficult and prolonged, sometimes requiring psychiatric counseling, anti-depressant medication or the use of specific individual coping techniques.

**“I tried to hide the fact that I used the machine, I put a tablecloth over it and then eventually I named it, I gave the machine a name to make it more acceptable to my kids.”**

**“I really loved my work, in fact I went into a clinical depression when they told me I couldn't work and had to stay at home with my three-year-old and live with the machine for the rest of my life. That was a big one and it took me about eight months, I used anti-depressants...”**

Some individuals accepted MV by managing their use of the equipment in ways that met their own personal and emotional requirements.

**“I try to stay off the ventilator unless I really, really need to be on it because I don't want my body to get used to not breathing by itself because I don't want to have to end up using the ventilator all the time.”**



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### 6.3.8 *Personal Philosophy*

Many participants, who have lived for years with the unexpected and unpredictable challenges of life with disability, seemed to have developed positive coping skills which enabled them to surmount, incorporate and adjust in a positive way to yet another encumbrance.

**“I just accepted it, because I went through my life having kind of everything's normal and then a major change would happen and I'd go from there so at that point I was kind of used to having events change things about, and I knew it was out of my control in a sense so I just kind of accepted it.”**

Such individuals held perceptions of life and a personal philosophy which enabled them get on with their life and enjoy it completely.

**“I never realize it until something goes wrong, like if I don't have my 100% support then I realize, “Hey I'm in a wheelchair and you can't do this yourself,” right? Otherwise I'm the type of person who never thinks about it, never worries about it, never grieves about it. It's something I had to do all my life and so I do it. I've always had a positive attitude about life... I've never thought there's anything I couldn't do...”**

### 6.3.9 *Personal Support Workers*

The increased need for personal assistance was perceived to be a factor which significantly interfered with adjustment to MV dependence and to the ability to enjoy a fully active and engaged life. The need for increased help, especially when suctioning was required, the reluctance or inability of PSWs to provide this, and the lack of personal support to accompany an MV dependent person into the community, instituted major impedance to independence and quality of life.

**“I knew it wasn't me that they were opposed to having. I knew it was the ventilator and the suctioning involved.”**

Support worker job restrictions (re suctioning) as well as the limitations imposed by inadequate funding to provide PSW accompaniment into the community were obstacles to the progress of the adjustment process.

**“The main change I find is that I can't spontaneously go out like I used to... now I can go more now than (when) I first got it (the trach)... I couldn't go anywhere without somebody accompanying me in case I needed suctioning and, for a long time after I got back home, I wouldn't go out, even out of the building for a little while, and then I decided, I said to myself you're so long between suctioning in your apartment, try going outside and you can get back in again before long and gradually I extended my (trips) around the block...”**

#### **6.3.10 Family Support**

The adjustment and acceptance of family members to participant's use of MV was varied but overall the introduction of MV did not appear to be an impediment to family life in any significant way. Generally, families were supportive and this was important to participants' own ability to accept MV and incorporate it into their lives.

**“...my family, especially my parents, are one of the reasons I was ventilated in the first place. I don't think I would have survived long enough without their support, and I've also been fortunate enough to have really good doctors... all my care staff are excellent, my brothers have been supportive, my whole family, especially when I was first ventilated.”**

**“I have a very supportive husband and son. I had great parents obviously who were determined that I was not going to be institutionalized all my life.”**

Several participants described issues related to noise when using the equipment at night and its effect on family members, particularly sleeping partners. A few found that their children had to go through their own adjustment process in order to become

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accustomed to the equipment, (influenced, in one situation, by the MV parent’s distress). However, this was also ameliorated by their pre-existing familiarity with parents’ wheelchairs.

Some family members even found MV comforting and a source of security. One father who participated in the study commented on how his adult daughters liked to go and lie down in his room with the ventilator running when they were upset because the sound of it had comforting associations for them.

In summary, adjustment to MV begins as soon as MV is introduced with no clear demarcation between the introduction and adjustment phases. Adjustment is a highly individualized ongoing process that is related to many factors, time and experience appearing to be the most important contributors. Other significant factors included health benefits realized, choice and control, social and personal perceptions of MV, loss of previous life style, equipment limitations, suctioning issues, mobility and travel barriers and acceptance by the family. These factors were also identified by participants as Facilitators, Satisfactions, Barriers and Dissatisfaction and are further discussed in these sections.

#### **6.4.0 Daily Life**

Participants described a wide range of daily activities that typified their daily living. These included necessary individualized personal care activities as well as a broad variety of activities associated with homemaking, employment, volunteerism, recreation and leisure, as well as socializing with friends and family.

### 6.4.1 *Personal Care Routines*

Self-care was reported by all participants to be a regular part of daily activity. Routines were often carried out at designated times and usually required some form of physical assistance that was directly related to general disability or ventilator and suctioning dependence. For the most part, these care routines did not significantly affect participants' ability to engage in other desirable daily activities. However, participants often acknowledged that these necessary personal care activities were time-consuming and occasionally counter-productive to accomplishing other, more enjoyable, activities.

**“... In the morning I get up, I do my bladder stuff and I do a bowel routine every other day, and then I shower, get dressed and then I get up (in the chair) ...it takes about three hours...”**

A few participants who required considerable assistance to perform self-care indicated that this dependency directly limited opportunities for social participation. This was particularly so when unpredictable suctioning requirements were present.

**“I go out shopping once in a while with my family, but I rarely get a chance to go out with my friends because I need suctioning whenever I go out. Although my friends have been trained they have never actually done that on me, so I don't feel too safe...”**

Some participants articulated that living with their disabilities was often a “lot of work.” Some described the need for more balance in their daily routines. Because of the complexity of their daily lives and the organizing and scheduling involved across

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multiple support systems (e.g. PSW support, transportation), it was mentioned by one participant that ventilator users have to prioritize their activities and choose those that are most meaningful to the individual.

**“... because it's getting too much, I'm tired, I have more things to do, I have to wash the vent, clean the tubes... you have to order supplies, suction catheters, gauze and stuff like that...”**

In spite of such ongoing daily limitations, the majority of our participants described the undertaking of these routines and activities of daily living as a necessary component and contributor to achieving a meaningful quality of life.

Engaging in “normal” activities was considered by all participants to be very important. It was impressive to realize the rich variety of activities that participants were engaged in.

#### **6.4.2 Homemaking**

One participant described immense pleasure in homemaking activities, such as cooking for her family and herself and gardening. Although she could not physically carry out any of the functional actions required by herself, she verbally directed kitchen activities with verbal instructions to those assisting her and clearly defined herself as the “cook”. In addition to cooking, she considered her ability to work in the garden as being a highlight of daily living that was strongly related to her quality of life.

**“I'm a homemaker. I love to cook. I love to preserve things, I love to bake and so my attendants do what I want them to do.”**

### 6.4.3 *Employment*

For some participants, engaging in employment or academic activities was central to their self-perception and attainment of life satisfaction. Reported professions were fairly diverse and included professionals, administrators and/or self-employed business owners. Employment was described as being important because it provided a mechanism for social participation, was part of defining one’s sense of self and was symbolic in that it demonstrated to society the ability to be contributing citizens. During the interviews it seemed important to participants that they were able to counter a common public perception of inactivity with an awareness that persons with disabilities aren’t just “sitting around.”

**“... The majority of my income comes from doing speeches and doing consultations, I travel out of town probably once or twice a month and usually for three or four days at a time...”**

**“Okay, well I get up at 7:00 and by 9:00 I’m at my desk and I do all the administration for two Daycare Centers which includes bookkeeping, scheduling, purchasing, paying bills, dealing with subsidy, dealing with government issues, dealing with everything that is current which there’s a million things, okay, so that takes me usually to after lunch. My husband and I’ll go down to the Centers and spend a couple of hours and then come back home for dinner and in the evening, if there is work to catch up on, then that’s ok.”**

**“Well, my painting is of foremost importance because I am on scholarship and I just stated painting shortly after my accident. “I have been painting about 28 years now too, so I’m always learning,”**

### 6.4.4 *Being Productive*

Participants cited the desire to engage in activities that were productive. Being “productive” was considered in a broad sense and included employment, volunteer

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work, and/or participation in self-fulfilling endeavors such as art, travel or recreational activities. A common element of these activities was the perception that individuals were pursuing self-initiated activities of their own choice.

**“Ya, my art became very important to me because it was the first thing that gave me a chance of independence because it was something that nobody could do for me, I had to do it on my own, so it became, very, very and still is, important to me. It’s important to me as recreational and a way of expressing myself and a way of expressing independence and hopefully becoming my income, so in a lot of areas that is important. Because I do depend on somebody for everything else in my life, literally everything in my life, but nobody else, no caregiver, no friend can do that.”**

It sometimes seemed that, given the degree of disability and the support needs involved, many participants were far busier than might have been expected.

**“I am involved in the management committee for our 24-hour support care, I’m also president of the OFCP for one more year, the Ontario Federation of Cerebral Palsy, I’m on the board of directors for the building. I’m on the board of directors of Participation House Toronto, which operates two group homes ... I belong to the Fellowship of Christian Handicapped.”**

**“If I’m not painting I’m on the computer doing stuff because I’m involved in housing for persons with disabilities and persons with severe disabilities. I’m also the president of the Disabled Sailing Association as well, which is a recreational outfit for persons with various different disabilities, and I’m going into schools and groups.”**

#### **6.4.5 Advocacy**

Participants described involvement in volunteer and advocacy activities as part of their daily life. Recognizing that their own personal experiences could be put to good use working on behalf of others living with disabilities, it was not uncommon for

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individuals to identify advocacy as an important life goal. A strong motivation for volunteer and/or advocacy work seemed to be the desire to give something back to the community and at the same time work towards removing existing societal barriers. Similar to employment, involvement in advocacy was considered to be an important element of self-perception, socialization and productive citizenship.

**“It’s quite full, my daily life is. I’m involved in the Peel-Halton-Dufferin training board, that means meeting frequently during the month and so on, and I’m the rep. for persons with disabilities so I advocate for them on the training board for Peel-Halton-Dufferin. I’m also the Peel representative for the Ontarians with Disabilities Act.”**

#### **6.4.6 Computer Access**

Using the computer for communication, research, volunteer work or accessing a range of media sources was identified as being a significant part of some participant’s daily routines. This was particularly so for participants who were less able to get out into the community. In these instances, computers were described as fulfilling a recreational and leisure need, i.e. being a source of entertainment, while at the same time providing an important connection to the community.

**“I surf the Internet, I check my email, play some games. ...I socialize with people here I know and (when) we’re in the computer room we usually talk there.”**

#### **6.4.7 Social Activities**

Activities which facilitated social participation, such as shopping, social outings, sports and travel were identified as important contributors to quality of life.



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**“Well, I play wheelchair hockey, I’ve played wheelchair hockey since 1985, I’m in the Hockey Hall of Fame, the first wheelchair person to ever score 50 goals in one year.”**

**“Oh, I have a very active social life actually because of being on the board and president of the sailing club too, I’m involved in that and that’s very social, that’s a very social event, you’re always interacting with people and going to regattas. I just got back from Victoria and I was on a regatta there.”**

#### **6.4.8 Family and Friends**

Significant emphasis was placed on the importance of activities involving family and friendship networks in daily life.

**...In the summer from May ‘til October we have a cottage so we go there Friday afternoon until usually Sunday night, sometimes Monday, depending on schedules and there we entertain and do the usual things that you do at cottages, have fun, etc. That takes care of my week and for recreation we like to travel, and we’ve been on some wonderful trips.”**

**“...I spend a lot of time with my friends, mostly just hacking around, we go to dinner or to each others homes, you know”**

**“ ...same bunch of friends for over twenty years, I met them when I moved here and I have a core group of friends from work, there are about five or six of us, we get together every two or three months...”**

**“...My brother comes over, my grandkids and my daughter comes, there is never a dull moment ...”**

In summary, although necessary daily personal care routines (which varied with degree of impairment and dependence) required significant routine daily time which took time from other more preferred activities, it was obvious that the daily lives of many ventilator users were typified by substantial involvement in many so-called “normal” activities. These activities included homemaking activities, employment, volunteerism,

advocacy, social, recreation and leisure activities as well as ongoing involvement with family and friends. Even those participants who faced challenges in achieving more independent community involvement were activity involved via computer and their network of family and friends.

### **6.5.0 Facilitators of Daily Life**

Facilitators were defined, for the purposes of this study, as supports which contributed positively to participants’ daily life satisfaction and the overall quality of life.

Participants identified a broad range of facilitators, including the support of personal support workers, family, friends, volunteers, and healthcare providers. Mechanical ventilation, personal attitudes, advocacy, financial security, housing, transportation, and ongoing health maintenance were important facilitators, with recognition also being given to government and agency programs that made supportive housing, attendant services, assistive technologies, financial income and public transportation possible.

The personal support provided by paid workers, family, friends and volunteers was mentioned most often, followed by MV and the ventilator user’s own attitude.

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**6.5.1 Personal Support Workers<sup>1</sup>**

Personal Support Workers (PSWs) were considered to be one of the most significant facilitators of daily life. Personal Support Workers are individuals trained to provide support with activities of daily living such as bathing, toileting, cooking, eating, etc. These personal assistants made important contributions to daily life by providing required care and services and, in some cases, emotional support and friendship. This was especially acknowledged by those participants who were involved in self-directed personal attendant programs.

**6.5.1.1 SELF-ADMINISTERED PROGRAMS<sup>2</sup>**

Participants who hired their own workers felt that, although they had to invest significant work in recruiting, training, scheduling and directing their support staff, investment of time and responsibility was worth the control and independence they achieved.

**“I think it’s really great. It’s changed my life a lot. I can go places now when I want to and where I want to...the guy I have with me is about my age, so we have things in common and we go places where I want.”**

**“It takes a long time to train them, about three months or so, and with the direct funding I have to look after all the payrolls and time sheets and various financial journals.”**

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<sup>1</sup> The individuals who provided paid personal assistance to participants were referred to using a variety of terms: ‘attendants’, ‘personal support workers’, and ‘self- managed aides’ were the most frequent. For the sake of consistency we decided to use the term ‘personal support worker’ to describe all of these categories. However, in doing so we recognize that there is a significant difference between an attendant who is hired, trained and managed directly by the consumer and the worker who is provided by an agency.

<sup>2</sup> Direct Individualized Funding (DIF) in Ontario and Self-Managed Care (SMC) in Alberta are provincial programs in which the individual requiring personal support receives funds directly from the province and accepts full legal personal and employer responsibility for setting up, hiring and administering the program, with respect to her or his own personal support needs.

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**“On four days of the week, I have the self-management aide comes in and she does my laundry and that while she's here, the housecleaning. If I want to go out, she can drive me to where I want to go, shopping and social events and church or whatever, as long as I schedule it within the time.”**

Some participants described an initial discomfort with the idea of hiring strangers to provide care, but found it to be a great benefit once they tried it.

**“...at first I didn't want it. I've never had anybody but family or really close friends bathe me or put me on the toilet. So I fought it at first and didn't get very many hours because I couldn't have cared less. Once I realized what a thing it could be...it changed my life totally.”**

**“And it enabled her (mother) to live also, to not have to look after me anymore so she could pursue her own things as well. So I was living with her for the last couple of years, I was living with her but I was becoming more independent from her because the home care was basically covering the whole day, so it was good.”**

Participants who lived in Support Services Living Units (SSLUs) also valued the PSW support provided to them; although they had less control over scheduling and the manner of providing care than did those who hired their own staff. Participants generally felt that most PSWs were flexible, caring and responsive to their needs, although some did expressed concern about English language competency and the lack of staffing within the SSLUs to meet all their needs. (e.g. staff to accompany an MV user into the community) Stability in employment of PSWs was considered to be an advantage.

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### 6.5.2 Family Support

Family support was provided primarily by parents and spouses and, in some cases, siblings and cousins. Family members also provided personal care with activities of daily living, suctioning, maintenance and operation of MV equipment as well as accompanying participants out of the house.

**“...right now my sister and my cousin are learning how to suction.”**

The significant emotional support they provided was acknowledged, as well as general support, advocacy and companionship. In some cases, family members made what were described as sacrifices, giving up jobs to stay home and provide necessary personal care. Support from family members frequently supplemented paid care.

**“...my wife stayed at home and I worked and it was only up 'til about three years ago that I really had any kind of help from a male nursing orderly... my wife would look after all those things but over the years, you get older, stress on your body, on her body I should say, after all these years...”**

When spouses were providing support, the need to maintain some boundaries between roles (partner and supporter) was raised by some participants.

**“It was a tremendous load for my wife to raise two young children and to have me as well relying on her more than the average spouse... plus all the homemaking responsibilities. That’s one of the reasons I was wanting to make sure I had as much in place in terms of home care because if you don’t take care of those things then all of a sudden you’ve got things eating away at your relationship that really shouldn’t be and they become factors, bigger factors than they need to be.”**

Aging of family supporters was cited as an issue in several interviews. Participants were concerned about the physical strain that providing care brought to their parents,

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and they were also apprehensive about what would happen in the future when their parents were no longer able to provide care. In some instances, these types of concerns had motivated participants to pursue funding to independently hire their own personal attendants with the support of government programs such as Direct Funding or Self-Managed Care. One participant had moved into a long-term care facility after living in the community when a parental care provider could no longer manage.

**“... it was getting difficult, mother's getting older and it's getting hard for her so I decided to move somewhere and uh, I knew about this hospital so this is where I wanted to come.”**

### 6.5.3 Friends and Volunteers

Friends and volunteers were cited as important facilitators in achieving their current quality of life. Many of these supporters had learned how to suction and operate MV equipment. They provided companionship and accompanied participants out into the community.

**“Well I have a friend and he can suction, so I go out with him sometimes, to the mall or movie, whatever.”**

One participant had organized a “support circle” of providers (paid personnel, friends and volunteers) who acted as her extended family. This theme of supporters being regarded as family was present, although less explicitly articulated, in other interviews. In some cases, individuals who started as paid staff or health care providers became close friends with participants. In other cases, distinctions were clearly maintained between roles.

**“I have a lot of support through my church and basically friends I've met over the years, nurses, I still keep in touch with nurses that nursed me when I had my accident so they've become friends over the**

**years and we still, we get together every Christmas for a little reunion type thing that we have and even my doctors, like my doctors are more my friends than they are my doctors.”**

#### **6.5.4 Social and Recreation**

The “social” and “recreational” life made possible by friends, volunteers, and family was identified as a facilitator to satisfaction with personal quality of life.

**“Oh, I have a very active social life actually because of being on the board and president of the sailing club too, I’m involved in that and that’s very social, that’s a very social event, you’re always interacting with people and going to regattas. I just got back from Victoria and I was on a regatta there.”**

**“...I spend a lot of time with my friends, mostly just hacking around, we go to dinner or to each others homes, you know**

#### **6.5.5 Accommodation – Employment & Education**

One employed participant described his employer’s provision of a personal rather than shared printer at work as a workplace accommodation which had definitely facilitated his ability to be employed. Others cited other accommodations, such as the provision of attendant support, work schedule flexibility or changed classroom locations as essential facilitators which had enabled educational and employment opportunities.

**“...and in my (work) which is really, really good, I can change the days I go in, the times I go in, my attendant's really good about that, just you know, kind of adjusting her schedule, she's very good about that, so, it's great.”**

### 6.5.6 *Mechanical Ventilation*

Use of MV was almost universally regarded as an important facilitator of participants’ ability to pursue the types of lives they desired because it provided the level of healthfulness, energy and mental clarity that was required.

**“When I go to bed at night at 9:30 I’m tired and I need to get on my machine and as soon as I’m on my machine I’m asleep in about 10 minutes, so at the end of the day, having been up at 6:00am... I need my ventilator so I can relax and go to sleep. It’s wonderful”**

For participants who had had polio, the availability of MV for independent use in the home had been the critical factor in their being able to leave hospital and move out into the community, sometimes after decades of residency.

Only one participant, who was a relatively new MV user (two years), felt that use of MV had not facilitated his daily life, but rather had impeded it. This individual associated having to give up his career with the introduction of MV during a critical health incident. This individual also relied primarily on his mother for personal support and was concerned about the changes that were looming as she aged and found it more difficult to manage his care.

### 6.5.7 *Personal Attitudes*

Positive self-image, self-confidence and ability to be proactive in making and acting on decisions were often cited as important facilitators in daily life, although not by all participants. Individual differences were present.



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**“I’m a very positive person. I figure there’s no barrier that you can’t get over if you try, so I really don’t have any difficulties or barriers that I can’t overcome. I’m very lucky with my life... extremely lucky to have everything I’ve had.”**

Having a positive attitude appears related to the ability to creatively solve problems encountered. Rather than experiencing their lives as difficult or problematic, participants appeared to accept that life is always challenging and one must rise to meet and overcome those challenges.

**“Some disabilities or things that have happened have been obstacles but they’ve also given me a chance to solve problems and experience life.”**

Accepting MV into their lives involved accepting the challenges it presented, such as learning to operate and manage MV equipment, training care providers in how to meet their needs around using MV, and organizing day-to-day lives in ways that supported their goals. Many participants demonstrated a positive and proactive attitude which enabled them to do this.

**“Well we all know about how long it takes to do things, that's part of the training of my staff is to get it to the point where they can do things in a certain period of time and for me that would be scheduling, if I know I definitely can't be late for something, then I know when to schedule any assistance, or else I have to get up an hour earlier or something like that.”**

**"Yes I train them, but it's as simple as ABC, just two shots and they know what they're doing. I train them myself and I train them within a day to take care of the ventilator... They're pretty smart, they know my numbers....if for some reason I'm not getting a good breath... I can tell them what to look for and they learn very quickly."**

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In some cases this meant accepting the fact that eating out in restaurants had to be arranged in a manner that allowed suctioning to take place without disturbing others or community activities in general had to be restricted because of ventilation needs.

**“...I avoid going anywhere in the morning if I can... I would be suctioned more often than the other part of the day and the week following my trache change too. I don’t usually go anywhere that week because the irritation of the trache change causes more mucous, a little more suction..”**

Participants felt it was important to take responsibility for oneself rather than depending upon or expecting others to do that on their behalf. While this aspect was not universally expressed, it was a common theme that ran throughout the interviews.

**“...it's not rocket science but you have to know these kinds of things and be aware of how these things work... but you don't have to take a course...”**

**“I couldn't breathe on my own until I learned how to frog breathe which was in the early '60s, but I probably spent less time in bed or on the ventilator when I became more active in organizational involvement and had more of a reason to do it and more of a purpose. It forced me to develop my frog breathing and I'd go anywhere between whatever... I guess 12 and 18 hours a day, depending on what my days were. I think the last couple of years, I take more opportunity to rest than I did before, and I think more than a deterioration it's just more of a recognition that it's a smart thing to do.”**

Associated with this self-responsibility attitude was a self-acceptance, and a self-image not solely bounded by disability or dependency. Participants tended to accept themselves and were able to articulate both their strengths and weaknesses. Aside from the requirements of dealing with health and disability related issues, they saw themselves as “regular” people going about the business of living their lives.

**“I could spend my whole life being disabled...I could spend my entire day being disabled and everybody would support me to do that but that’s not much fun.”**

One statement we particularly liked was a description of a sign that a participant has attached to the back of his wheelchair, which captured the openness that we found in the participants overall - a willingness to share with us some insights into their lives:

**“My legs don’t work but my mind does. I’m a great guy to talk to. Feel free to ask questions as they are the key to knowledge.”**

### **6.5.8 *Family Support***

The attitude and acceptance of family members also contributed to participants’ positive attitude.

**“It was fine, my children, I don’t think they ever realized I was in a wheelchair. I never realize it until something goes wrong, like if I don’t have my support, 100 per cent support, then I realize, hey, I’m in a wheelchair, you can’t do this yourself, right, but otherwise I’m the type of person that never thinks about it, never worries about it, never grieves about it, it’s something I had to do all my life and so I do it.”**

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### 6.5.9 Assistive Devices

Assistive technologies, such as the ventilator and related equipment, customized wheelchairs, computers and adapted vans were cited as facilitators to daily life.

Although not explicitly stated, participants appreciated the provincial government and agency programs which provided the equipment, usually on a cost sharing basis.<sup>3,4</sup>

**“I love this chair, it's a really good chair, it's getting old, it's going to need to be replaced but this wheelchair and the one before it were almost like, I would say a breakthrough in terms of actually being good for the person in the chair as opposed to other people and it's been really helpful to me, it tilts, it reclines, I can drive it with my mouth.”**

**“For me, one of the big advantages (MV support program) is that I have someone to call for information, assistance or support whenever I feel that it is necessary. This takes the concern and worry out of equipment failure, or the question of what to do in case of an emergency.”**

In Alberta, individuals disabled by polio are eligible for additional financial support from the Alberta Polio Program<sup>5</sup> for equipment, medications and other necessary disability related products that are not covered by the provincial assistive devices programs.

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<sup>3</sup> The Ventilator Equipment Pool (VEP) in Ontario provides ventilator equipment and related equipment maintenance support. The Respiratory Home Care (RHC) program in Alberta provides routine clinical home based respiratory therapy support in addition to ventilator equipment support.

<sup>4</sup> The Assistive Devices Program (ADP) in Ontario provides prescribed disability related assistive technology to eligible clients, such as wheelchairs, orthotics, computers, on a 75/25% cost shared basis. The Alberta Aids to Daily Living (AADL) is the comparable program in Alberta. There are differences between these two programs in terms of equipment provided, eligibility criteria and cost sharing arrangements.

<sup>5</sup> The Alberta Polio Program was instituted by the Alberta Government during the Alberta polio epidemics of the 1950s to help defray the tremendous expenses incurred by individuals paralyzed by polio. During that era, government funded hospital, healthcare and disability equipment programs did not exist and individuals and their families had to bear the financial burden directly.

**6.5.10 Advocacy**

Advocacy emerged as a facilitator of daily life for many participants. They benefited either from their own advocacy initiatives, pursuing improvements to supports and services that would benefit either themselves or others, or they benefited from the advocacy undertaken by family members and advocacy groups.

**"I still knew enough of the people in key positions in the hospital and I knew who to call to ensure that medically I wasn't going to be put at risk."**

Some participants expressed a form of “fight-till-you-win” mentality, basically saying that if they really needed something, they would pursue it until they succeeded – in other words, no barriers were going to stop them from taking their lives in the directions they needed and wanted.

**“Lobbying is a key element in this community.”**

**“...When they put the three thousand dollar cap on, they said I was over it and so they cancelled (my funding for services) and said I had to move into a nursing home but I fought back, I lobbied....”**

**6.5.11 Accessible Housing**

Having stable, affordable, accessible housing, although less frequently identified, was not surprisingly, an important facilitator of daily life for a number of participants. Conversely, participants who lacked appropriate housing or who were apprehensive about losing the housing they currently had, felt that housing issues negatively affected their quality of life.

**“Well, the building's been specially designed so all the light switches, door locks, stove things, the laundry, there's one laundry room, they're all wheelchair accessible so that makes it unique. And they have wheelchair-washing areas. The parking is adequate for my van so I can park indoors and not be out in inclement weather.”**

### 6.5.12 *Financial Security*

Having an adequate basic income was regarded as an important facilitator to quality of life for those participants who felt that they had one. Adequate income allowed participants to exercise choice in their personal lives and to participate in recreation, travel and other personally valuable activities. For some participants who had been long- term residents in hospitals, receiving individualized funding for personal support with activities of daily living had facilitated their moves out into the community.

**“...once I got the home care straightened out, that's when I decided I could move out of ( healthcare facility), I didn't want to move into the community, sort of, to have that full-time need without a full-time solution. So it wasn't until we got home care and funding straightened out with government funding that I decided to move...”**

Participants receiving government support (income replacement or disability pensions)<sup>6</sup> appreciated the financial support they received but cited restrictions such as loss of eligibility through employment as a disincentive to work. Much needed financial support for the cost of medications and assistive technology was tied to eligibility for income support, and participants who wished to move off governmental programs and into paid employment were concerned that the loss of coverage for medications and equipment would be more than they could replace through earned income.

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<sup>6</sup> Ontario Disability Support Program (ODSP) in Ontario  
Alberta Assured Income for the Severely Handicapped (AISH) in Alberta

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The family of one participant had taken out Polio Insurance (which was available in both Ontario and Alberta) during the epidemic days and this was an additional source of funding for polio related personal support services and supplies or equipment.

#### Transportation <sup>7</sup>

In spite of many frustrating problems with municipally operated specialized parallel transportation systems, participants who relied on these publicly funded services recognized and the important role they played in enabling them to be involved within their communities.

Although neither trained nor expected to provide personal care, in some instances bus operators had provided critical emergency assistance, such as reconnecting ventilator tubing when the driver noticed a participant had stopped talking or helping with a trache problem.

**“...I have a button in my throat and they don’t know what the heck it’s for really. On occasion I’ve had to ask the driver to take the button out of my throat for me because I started to choke...”**

Some participants have used regular bus and subway systems, in cities where they exist, and felt their mobility had been facilitated by the flexibility, reliability and spontaneity such services provide.

**“..I’m usually with my home care worker so...I’ll drive my chair to the bus stop, get on and my home care worker will have to lift the seat up so I an drive into it and then they help with the big doors, my chair can’t do it...”**

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<sup>7</sup> Wheel-Trans in Toronto; DATS (Disabled Adult Transportation Services) in Alberta, Participants living outside metropolitan Toronto but within the GTA (Greater Toronto Area) must use also use other connecting accessible transportation services which have their own criteria and pre-booking requirements.

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**“...the systems really good from where I live. I take the bus to the LRT station, which is the subway and then I go straight to the Coliseum... they just introduced new trains where they have a lip that lowers down so it becomes a ramp.”**

**“I prefer the flexibility and reliability of regular transit, using low floor buses and LRT.”**

Having one's own transportation, rather than having to rely on public para-transport systems was an important facilitator for those who owned their own vehicles. In fact, one participant felt that having his own lift-equipped van was the most significant facilitator in his life.

### **6.5.13 Health Management**

Participants described health management as an important facilitator because maintaining health enabled them to engage in the activities they enjoyed. When a participant was involved with healthcare practitioners who understood and supported their needs, they were held in very high regard.

**“....and I've also been fortunate enough to have really good doctors... all my care staff are excellent.”**

**"I usually avoid going to doctors .....but I have a wonderful doctor... She'll give me anything I want and she trusts me. She knows that I know my body better than she knows it."**

**“I think they really learned ... that people can have an active life even though they have a chronic condition and they give us lots of room to deal with our issues and if they bring on the heavy medicine.. like if I say I want to do it without a trache, they listen to me, right, and if I say I want to deal with this without antibiotics as long as I can, they'll listen to me, on the other hand, if I phone up and say, this is happening fast, can I have an antibiotic right now,**



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they'll listen to me, right, so it makes it a whole lot easier for just figuring out how to deal with it each step of the way.”

“I went through emergency, the ambulance come and took me, my wife brought along my machine, took it into the hospital, set it up. They had their respiratory therapist come in but all they did is just watched, so my wife set it up. I said I need my ventilator and there was no questions asked... so I mean they said, here's a person that obviously knows what they're talking about and understands what their needs are and can communicate them and away you go.”

“I think they had to put me in a ward, I can't even remember exactly, but I think they had to put me in a ward where the nurses knew about ventilators already, so that wasn't a problem.”

Some expressed satisfaction with the ventilator and respiratory home support program.

***“...I think I'm pretty satisfied. I don't have to worry about the funding.” “... They take care of everything. “***

The participants in this study regarded maintaining general health as a strategy for supporting daily life. Some participants used alternative forms of medicine, nutritional supplements and diet in order to support immune system health and energy.

### **6.6.0 Satisfaction**

The participants we interviewed, (with one exception) expressed general satisfaction with their lives.

**“I think most aspects of my life I'm pretty satisfied with, great family, great friends, and a great job.”**

As might be expected, many personally essential facilitating factors were identified as sources of satisfaction, (e.g. family support, personal support workers, mechanical ventilation, adequate income and housing.) Other less essential sources of satisfaction that participants were often proud of achieving, (often in spite of many barriers) were productive contributing activities such as employment, advocacy, volunteer work and social activities.

### 6.6.1 *Family*

Having supportive family involved in one’s life was a source of satisfaction for almost all participants regardless of whether they lived with family or on their own.

**“I’m satisfied with a family that cares about me and they’re here to help me, that’s the good thing, some people don’t have that, you know, some people have either older parents who can’t take care of them or you know they end up somewhere like (a long term care facility) to take care of them. It’s good to have parents that care a lot. They’re there for me.”**

**“Just being with the family and getting the support I need so I can stay with my family.”**

### 6.6.2 *Personal Support Workers*

Having good support from personal support workers was identified as a source of satisfaction with their lives. An integral part of this satisfaction was being able to hire, train, schedule and manage attendants, either with funding from a self-managed care government program (DIF, SMC) or their own personal income.

**“My workers are well paid by me. And they deserve every penny of it because they’re good, they’re very willing to do what you want done and they don’t complain...”**

### 6.6.3 *Choice and Control*

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Having greater control over the various supports that participants need in order to participate in “normal” daily activities was an often cited source of satisfaction.

**“I've just started basically on this self-management attendant thing and I think it's really great, being able to control how you need things that have changed my life a lot.”**

**“And I have a lot of control in my (work) which is really, really good... I can change the days I go in, the times I go in, my attendant's really good about that, just you know, kind of adjusting her schedule, she's very good about that, so, it's great.”**

**“I'm satisfied that I have a lot of freedom now because I was able to make enough money to create choices for myself by having home care workers, and that was the biggest thing. I think when we got self-managed home care, the funding for that, I could start choosing who I wanted to be with and work for me and that allowed (me), I think, to be more social and get out and (have) more freedom.”**

#### **6.6.4 *Mechanical Ventilation***

While few participants explicitly identified use of MV as an aspect of satisfaction with their lives, it clearly was part of the foundation on which satisfactory lives were built for all but one participant. Ventilation provided participants with the energy, healthfulness and mental clarity required to lead the types of lives that gave satisfaction. For some, mechanical ventilation was described as providing life itself.

**“...if it wasn't for the ventilator, I wouldn't be here.”**

**“I think a lot of people don't realize how easy it is to have a trach and because it is so mechanical it makes you feel like you're sort of a robot in some way but you get used to it.”**

**6.6.5 Housing**

Having good, affordable, accessible, and for some participants, supportive housing with personal support services, was a contributor to satisfaction in life.

**“...The building's been specially designed so all the light switches, door locks, stove things, the laundry, there's one laundry room, and they're all wheelchair accessible. So that makes it unique. And they have wheelchair-washing areas. The parking is adequate for my van so I can park indoors and not be out in inclement weather.”**

**6.6.6 Community Involvement**

Involvement in some form of employment, volunteer work, leadership, social or educational activity was an important source of satisfaction for almost all participants.

**“I have an income that allows me the freedom to do a lot of things I never dreamed I would be able to do and I enjoy working, I'm a workaholic actually.”**

**“I think I'm satisfied because I'm finishing a very successful year of being president for the Disabled Sailing Association and it's ending on a really good note ... I never thought I could do it, I mean, it wasn't easy, it's a hard job, it's a big, huge, very big responsibility to take a hold of but I am pleased.”**

**“I think that the fact that I've worked for this many years, that, where a lot of people maybe don't have jobs, certainly that's one source of satisfaction, you feel good about yourself. I'm also involved in various organizations, either through being the treasurer or things like that, so I'm involved in the community to a certain degree.”**

**“...my art became very important to me because it was the first thing that gave me a chance of independence because it was something that nobody could do for me, I had to do it on my own.”**

**“I feel I'm lucky that I can get into university, considering the level of disability I have, I never thought this could happen when I first got paralyzed. I like playing around with computers a lot but I never thought I would get into computer engineering.”**

### 6.6.7 Education & Advocacy

Participants were satisfied with the role they played in advocacy, awareness and education about life with disabilities.

**“And I’m pleased that I’m able to educate people in the ways of it, that persons with disabilities, they just don’t sit around and watch TV, they have lives and they do things with their lives.”**

Sometimes satisfaction with life came from unexpected things, like having a really comfortable, appropriate wheelchair or owning one’s own vehicle.

**“... One thing I'm happy with is I love my car, I love cars, my personal assistants are good...”**

More commonly, satisfaction was expressed as a cluster of contentment related to personal achievements or life events in an integrated, global, kind of way.

**“Well, the fact that I'm able to work and run a household and be out in the community... that's what I'm most satisfied with.”**

**“I've got my own house, like who can ask for anything more, and my garden and my clothesline in my backyard, and a van to take you out if you’ve got to go, my doctors are all just up the street and it's good.”**

**“Having my own place, even though with an architectural drafting background I do want to design my own home, and work, and the fact that I love volunteering as well.”**

## 6.7.0 Barriers in Daily Life

Barriers, for the purpose of this study, were defined as obstacles or limitations which prevented participants from achieving a satisfactory quality of life.

Participants described numerous barriers in their daily lives as they reflected on their experiences of living in a world not designed for persons with disability, barriers which constantly challenged personal independence, security, sense of dignity, health and autonomy. Some of these related to physical needs arising from personal disability, such as mechanical ventilation and suctioning, but the vast majority of barriers were seen as external to participants and physical or social in nature (e.g. inaccessible buildings, public stigma). Bureaucratic obstacles in accessing necessary support programs, tenuous income security, poor quantity and quality of required services, finding appropriate and knowledgeable healthcare and coping with public transportation systems were the most frequently cited barriers and sources of frustration in daily life.

### 6.7.1 Suctioning

Although the use of mechanical ventilation itself was not considered an impediment to satisfaction with life, the needs that some MV participants had for personal assistance with suctioning often produced major obstacles which had to be contended with,

**"I find that they're all very intimidated by the ventilator and suctioning and so on at first. I try to basically reassure them that they are really simple things that take practice but are not hard to master."**

**"I haven't needed suctioning but if I did it could be a problem because not all of the staff knows how to do it."**

Many participants living in supportive housing who required suctioning assistance when out in the community, (especially if this need was unpredictable or frequent) were severely restricted in their activities of community living by the lack of available funding

to provide a support staff person who is trained and comfortable with suctioning) to accompany that person.

**“It almost caused everybody to quit work, almost.”**

### **6.7.2 MV Equipment**

Ventilators and related equipment, although obviously appreciated, were described as an impedance to travel and social or recreational events, such as visiting friends or attending concerts and movies, because of the size, weight, look or noise of such equipment.

**“...although I was suctioned a lot, for me to hear it or watch somebody being suctioned.., it just makes me want to gag.”**

Some participants were frustrated because they knew that smaller quieter, more portable ventilators and more efficient suctioning machines were on the market but not available to them through government programs. One participant felt so limited and frustrated by the suctioning machine provided that he had privately purchased a preferred, more efficient machine.

### **6.7.3 Building Inaccessibility**

Physically inaccessible buildings and other aspects of built infrastructure were universally acknowledged as impediments to independence and choice, although participants spoke of these issues in a matter-of-fact manner which seemed to say “this is our daily life.” Participants cited physical inaccessibility as pandemic.

**“90% of the world is inaccessible.”**

**“Wheelchair accessibility is always a problem.”**

**“There's practically no parking downtown that will take a raised van. Even my van, which is not raised, won't fit in the majority of them so I've been lobbying to improve the parking situation. And it's very bad at hospitals, there's insufficient disabled parking available, a lot of it is very expensive,”**

Furthermore, claims to accessibility by restaurants and other public venues often proved to be false, reflecting a lack of societal understanding about what accessibility actually requires.

**“Washrooms that say they're accessible when they're not really accessible.”**

**“...When I go on vacation I have to call ahead and make sure the hotel rooms/motel rooms are accessible, make sure there's an outlet with three prongs in there for the respirator, for the wheelchair to charge it up. When I was going to Collingwood, I called ahead, decided to go up there ahead of time and the places that were mentioned to me (as accessible weren't.”**

#### **6.7.4 Public Attitudes**

Architectural barriers that limited physical access were perceived to be related to societal attitudes about disability and to a lack of social responsibility in supporting and accommodating disability. The visibility of participants' disabilities and their evident use of assistive technologies such as wheelchairs and ventilators were considered to be triggers for social stigma about what it means to have significant health or mobility-related needs for support.

**“I still find a stigma in the public's eye with the wheelchair, the trache, that is why I have a sign on the back of the chair.”**

**“...some people in public, I think they think of it (requiring ventilatory support) as life threatening.”**



**“...as far as ventilation, I personally feel there's still a real stigma, maybe that's not the right word.”**

### **6.7.5 Supportive Housing Programs**

MV participants living in, or hoping to be accepted into, supportive housing environments sometimes encountered prohibitive barriers, especially if assistance with suctioning was required.

**“...people cringe when they see this thing on your neck. Oh, I don't want to look. It might hurt... obviously it's a tube inside someone's neck... my, there's a lot of air sounds when you talk and so on...”. They tend to look at you as though you're an alien or something. But once the hurdle is overcome they realize, hey, you're just another person!”**

Intrinsic fears about performing an “invasive” procedure and the assumed or actual increased work load often posed major obstacles to obtaining supportive housing following tracheotomy.

**“The staff was not willing to take me back with the ventilator because they thought it would be a horrendous amount of extra work and responsibility and I might die on their hands.”**

### **6.7.6 Home MV Programs**

The Ontario VEP (Ventilator Equipment Program) loans medically prescribed ventilators but, unlike the Alberta RHC (Respiratory Home Care Program), does not provide associated ongoing clinical support. Some Ontario participants were critical of the withdrawal of clinical support which occurred when VEP was initiated and vendors withdrew their home based RT services.

**“...she would follow up with me ...did several night studies and I was doing great...she'd check the settings and that kind of thing every three to four months and then the ventilator equipment**

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**pool came into being and somehow xxx (vendor) wasn't supposed to do this follow-up.... It's not the informal process it used to be before –which was great.”**

Participants in both provinces lamented the fact that accessing the ventilator program services was not as easy as it used to be, and this has provided an additional barrier in their daily lives.

**“it's more difficult to get what we need as a ventilator user today than it used to be. ...more rule laden and less flexible... that's the rules, that's the policy, rather than that's what would work best for you.”**

### **6.7.7 Income Support Programs**

Participants accessing governmental financial support programs cited income limitations that inhibited their ability to engage in paid employment. For example, government income support programs included coverage for medications and equipment and if a participant took paid employment they would lose not only income benefits but also their medical and equipment benefits.

**“...They want you to try to get off the system but then if you try, you either live in poverty or stay on the system because you're not allowed to make more than so much a month, so basically there's no way I could, I couldn't live on my own but even if I could live on my own, I'd still be stuck in my mother's house because no way you could afford an apartment and medical stuff and food and everything else because they won't let you.”**

While some participants felt that they could probably earn enough income from employment to support themselves, they were not confident that they could sustain employment or earn enough to cover medications and equipment as well as their other expenses. This vulnerability kept them tied to the income support programs and out of

the paid labor force. In some cases, spouses were affected by the same considerations.

**“...Your spouse is only allowed to make \$700 ... a month and if they make more than that, they start taking away from your benefits and so we can't afford that so he just works part-time.”**

### 6.7.8 *Bureaucracy*

Participants were appreciative of the broad range of services and they required to lead their daily lives, (e.g. PSWs, MV equipment programs, housing programs and health services) but also frustrated by the many barriers involved in accessing these programs. As one participant said, the often stated program goals of helping persons with disabilities to lead autonomous lives in the community were undermined from the outset.

**“...the very services that are supposed to help you be more independent and get some autonomy are the ones that destroy it and make it impossible because their systems... they make it so difficult to get what you need.”**

The processes required to access supports and services and to ensure accountability, were described as heavily bureaucratic and time-consuming, often requiring multiple, repetitive layers of documentation in order to demonstrate eligibility for access, compliance with regulations and appropriate handling of funds such as those received within the self-directed PSW programs.

Cutbacks in staffing of governmental operations and social services further complicated participants' ability to acquire the things they needed in a timely manner

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and, related to this, some participants articulated what they perceived to be erosion in the level and quality of supports and services.

**“...so they have cut us back now to where everything to do with our care is handled by one case coordinator at (the) home care office who has probably fifty clients or more and one OT who also has fifty clients or more. So if I phone the OT now and say I need to talk to you about something that I need, like elastic stockings, or a cushion. She'll have to set me an appointment which may be two, three months down the road because she's so overloaded and yet we can't get them without her signature. And our case health co-coordinator can't make that signature, so it's a real bureaucracy going on.”**

### 6.7.9 *Public Transportation*

Publicly funded wheelchair accessible transportation systems were seen as a barrier to quality of life by all participants who relied on them.

**“I guess the biggest factor is getting to where I need to go on time, especially if I'm waiting for personal care.”**

The effort and frustration involved in orchestrating reliable transportation in conjunction with other scheduled daily requirements was simply too complex and exhausting for some participants who now avoided having to use the services.

**“...You have to wait an hour; you have to be ready an hour ahead. When they pick you up you have to be willing to ride for at least an hour or more to get to your destination. And then you need another hour to wait to return. If you're not right there when they pick you up, they won't pick you up. Sometimes they don't show up anyway, then you have to phone them to find out where they are, scheduling has been a real problem.**

Extensive and unpredictable waiting, late arrivals and departures, long trips, restricted hours of operation, advance booking requirements<sup>8</sup>, no on-call demand or

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<sup>8</sup> Wheel-Trans – one day advanced booking requirement  
DATS – four to ten days advance booking requirement

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emergency services, and ride unavailability made it difficult to carry out activities of community living. Some participants found that the unreliability of interfered with their ability to get to work or school on time or even their ability to accept employment opportunities.

**“I'm spending four hours minimum (getting to and from a part-time job), and then having to come home and work and do my other part-time job, you know, and then am I making any money or is it worth all this trouble?”**

In an emergency situation, such as when an MV user (without his own vehicle and driver) has to seek urgent medical help or go to a hospital emergency, particular difficulty is encountered because rides can only be booked in advance.

**“Now you have to schedule three days before the event, which means that if you have a sudden emergency you can't get a ride with them.”**

Ambulances cannot accommodate a wheelchair and, if an ambulance is the individual's only way to get there, the individual cannot then take such public transportation back home because she/he does not have her/his wheelchair and also cannot book the ride on the day and time it is. If the individual takes an ambulance home (often the only alternative) he/she does not have the money to pay.

**“If I have a medical emergency and have to go to the hospital by ambulance, they won't take my wheelchair... so I get over my emergency and have to go home ....have no wheelchair to be able to ride in DATS. An ambulance ride back isn't covered by any assistance. You'd have to have payment as soon as you get home and sometimes you didn't expect this emergency so you don't have this extra cash available.....and DATS doesn't work at night so ...you couldn't go home until it starts in the morning, and even then it's not likely then can book you in.”**

## 6.8.0 Dissatisfactions

Participants’ dissatisfactions with life arose from the barriers they identified. Externally imposed constraints such as accessibility, attitudes bureaucracy, income, quality of services, and transportation tended to be the issues identified rather than dissatisfaction with dependence on MV technology or with being disabled, although the latter were mentioned by at least one participant. Issues not previously mentioned as “barriers” concerned health care and the burden of work associated with living life as a significantly disabled person.

### 6.8.1 *MV Technology*

Participants were dissatisfied with the size and noise of MV and suctioning equipment, and found that the design and look of these machines limited their ability to get out of the house and enjoy recreational and travel activities. For some participants, just contending with assistive technology and all the daily challenges it posed, including maintenance, was a source of dissatisfaction, but one that had to be accepted because there was no alternative available.

**“...I'm even having a hard time just accepting living like this on a daily basis in a wheelchair and a ventilator, so it's just hard.”**

### 6.8.2 *Inaccessibility*

Lack of general accessibility, including the lack of accessible housing, was cited as a source of dissatisfaction by all participants. The pervasive lack of understanding of what physical accessibility truly means was frustrating, especially when locations

described as or confirmed to be accessible, often turned out otherwise and new inaccessible facilities continued to be built. Participants could not travel secure in the knowledge they would be able to get into the places they planned to visit.

**“There's a perceptual difference of accessible, for example one motel had three steps going into the motel room, but once you're in the motel room, it's fully accessible. That's fine for visually impaired individuals or hearing impaired person but a person in a wheelchair can't get up.”**

**“...The new theatres have changed, it used to be most of them would have seating for the disabled at the back and with the newer theatres, the seating is at the front so I don't find it very enjoyable sitting 15 feet from the screen. I guess from their point of view as long as they meet the minimum building code then they've done their job.”**

### **6.8.3 Societal Attitudes**

Lack of societal acceptance as a person with a disability, a person who uses assistive technology such as wheelchair and ventilation, was also cited as a source of dissatisfaction by a few participants.

**“Ventilation is such a rare thing most people have never encountered it before”**

**“I think they're so overwhelmed that they're afraid to stare directly at me but I know I'm being noticed...”**

**“I guess one of the things is acceptance that we're not in a ICU because we're using it, ventilation.”**

### **6.8.4 Bureaucracy**

Frustrations in accessing government and social agencies for necessary personal and financial supports were identified as a source of dissatisfaction.

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**“I am also weary of the continuing hassle of dealing with government in health related organizations since it can take forever to find the right person to get something approved/done/ordered/etc. I also find it frustrating trying to find many types of service (educational, financial, health, etc) that are accessible and meet my unusual needs.”**

**“it's unbelievable how much work you have to do to get it.., you can't just roll in and say "listen this piece of tin is 6 years old, it's time to think about replacing it." You have to go through all kinds of assessments and that's OK from a taxpayer point of view. I can understand...but it takes time and I don't have a lot of time.”**

### **6.8.5 *Reduced Support***

One participant, who was living in a long-term care facility, found that concerns about personal safety due to reduced staffing were affecting his quality of life and inhibiting his willingness to take the risk of moving out into the community.

**“At first I was thinking of going out to the community but I couldn't make up my mind on whether I should or not. I didn't think I would be safe but now with the cutbacks, it doesn't feel like I'm any safer here, but I'm still not sure if I should go into the community, I'm not sure.”**

### **6.8.6 *Transportation***

Frustrations in using the public wheelchair transportation systems were identified as a source of dissatisfaction which interfered with quality of life.

***“I've been booking Wheel-Trans or its equivalent now since coming to Toronto, I don't think we can depend on Wheel-Trans as much as we used to be able to, I've noticed a change in the last couple of years.”***



**6.8.7 Burden of Work**

Constantly organizing, scheduling, making appointments, training, explaining, directing, filling out forms and coordinating the many services and programs on which participants depended every day of their lives was never mentioned as a “barrier” to achieving a satisfactory quality of life, although the burden of work involved was certainly an expressed dissatisfaction. This was identified as one of the disadvantages of Direct Funding/Self Managed Care programs, although the benefits of such programs were considered to more than offset this disadvantage.

**“I could really use a business manager or some kind of a person Friday as well, cause I don’t get around to doing my invoicing, there’s a lot of that stuff that doesn’t get done very well because I’m trying to be my own administrator.”**

**“...between hiring, training, scheduling, like you say, looking after grants, dealing with wheelchair stuff, car stuff, on the support side of it, it's like if the ramp needs a new cable, that kind of thing, I have two hours a day (of administration work) on average.”**

**6.8.8 Healthcare**

Health care services, although not considered a “barrier” to achieving a satisfactory quality of life, were frequently cited as a source of dissatisfaction.

Although not an intended topic of investigation per se, dissatisfactions with healthcare surfaced so frequently and often so emotionally, it was clearly evident that healthcare support was a fundamental contributor to ventilator users’ quality of life. The participants in this study, by virtue of their disabilities, tended to require significant support from the health care system. Good, even adequate, support was not easy to

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achieve for a number of reasons, such as lack of specialized knowledge, inaccessibility, transportation difficulties, limited staff resources and negative past experiences.

#### 6.8.8.1 LACK OF KNOWLEDGE

Although some participants had found supportive general practitioners who understood their needs, others felt concerned and vulnerable because of their lack of knowledge about ventilator dependency.

**“I am not satisfied with the quality of medical care that I am receiving from my GP since he is not terribly familiar with respiratory issues. I am in the process of switching GPs and am hoping for an improvement in the situation.”**

**“He keeps saying maybe I'll come off the vent. I already told him 1000 times it's not going to happen... It's not going to get better, it gets worse. “**

One participant felt that ventilator users have highly inter-related needs that need to be understood in terms of the “whole” picture and most family practitioners don't have the time for this.

Some participants were still upset that their respiratory failure had been improperly diagnosed by physicians they considered to be experts in the field. In one situation, the participant had nearly died. In another, it was the participant herself who was so unsatisfied with her initial consultation that she researched her own symptoms, and then went to another doctor for confirmation and further investigation.

**"Giving me an answer like "it's your personality" it's just not acceptable, plain and simple.... I mean, it's tantamount to negligence, it really is"**

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“...with that specialist that we went to first, they saw my feet that were swollen, they didn't really say anything, they made me an appointment for a month later for a sleep study. If I waited a month, I would have died.”

“I just described... headaches in the morning, achiness and she just said "put your head back, now push it forward, hold it up straight... a year and a half later I'm still feeling the same and getting worse. I'm falling asleep while I'm driving my chair at the mall, I'm banging into signs... like it was really unreal so I thought this can't be normal... I'm a rehab counselor... and our students circulated an article on sleep apnea and I read it and said this is me in so I went to the hospital again and this time I saw someone else and I said "I have sleep apnea" so he asked me to describe what I was feeling and I told him exactly what was in the article was me and he says "you're probably right, you need a sleep study.”

#### 6.8.8.2 NOT UNDERSTANDING THE PRE-EXISTING DISABILITY

Participants were dissatisfied with the tendency of healthcare practitioners' to focus only on the primary presenting problem, such that underlying respiratory or disability needs were neither properly understood nor properly addressed.

“...That was a frightening part there, realizing that the hospital wasn't really, they must have had a respiratory section but the doctors that treated me, they didn't know a thing. They were concentrating on the knee...”

“I learned a long, long time ago, doesn't matter if you've got a nurse's uniform on or some white overcoat doesn't mean they understand neuromuscular disorders. Don't make that assumption, so I never make assumptions anymore about what they know and don't know.”

“...and (if) you have a pre-existing condition, they can kill you. They don't necessarily know that condition, nor do they necessarily really care and I think you can be unnecessarily at risk and if you go into a situation like that and have time to prepare and you can force a dialogue and interactions so they can get an understanding of what your pre-existing condition needs are then you have a much better chance...”

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**"They didn't have the understanding or background about pre-existing conditions or the implications of that. It's like if you stick the needle in a person's arm with muscle it's not going to be the same as sticking it in one who is skin and bone. Or the readings of such things as PCO<sub>2</sub>, oxygen saturation, breaths per minute, all those sorts of different readings which would be considered normal and sometimes move with the pre-existing condition. The only way you can understand that is to dialogue and interact, which is not something you always have time for. Sometimes they exacerbate the situation rather than improve it."**

Because of this perceived lack of knowledge and inability to provide appropriate integrated care many participants believed it was dangerous and “putting your life at risk” to seek care from unknown practitioners, to go to a hospital emergency or allow yourself to be admitted.

**"I don't go until I absolutely have to so I don't get long waits because I'm already an emergency by the time I get in. It's the only way to get good care is to wait till you have to"**

**"I can't sleep without the ventilator so I always pack the ventilator with me. This is given me some blessings because when I arrive with the ventilator, they're forced to get in RT... they don't want to keep me too long if they don't have to, so they'll process me through the system as fast as they can."**

**“And the fears that you have especially if you're severely disabled and you can't use a call bell system, well how would you feel if you, I mean, the hospitals are short of staff as it is, you haven't got a voice that carries to yell help, you're depending on somebody that's beside you, a patient that is heavily sedated isn't going to be able to push a call bell for you, it's a scary thing.”**

### **6.8.8.3 ASSUMPTIONS ABOUT DISABILITY**

Participants expressed concern about being seen as a “lesser” priority when they arrive at a hospital, because of their obvious disability and assumptions about their inabilities and quality of life, based on their visible appearance.

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**“There are some basic assumptions when a person encounters someone in my situation and condition,... this person in front of you who’s 55 years old with a body that’s somewhat deformed, if you don’t interact with them you don’t know if they’re a vegetable sitting in that chair... or an intelligent human being...”**

**“.. if it’s this guy over year that looks able-bodied, we can get him out of here compared to this other fellow over here who’s got all these deficiencies. Which one do you put your resources and your efforts into?”**

**“...this is not a person that’s a waste or is on their way out but someone who’s a human being that we can actually learn from and work with.”**

Even being in an ICU, where healthcare professionals are experienced with ventilators was perceived to be dangerous. Some participants cited traumatic incidents of medical misadventure as validation for their strong opinions and reluctance to seek re-involvement. Additionally, they complained that neither they nor their family members, friends and paid attendants who knew them well were listened to.

**“...One scary incident, the nurse accidentally turned the volume off on my ventilator and my dad was with me and he could tell something was wrong and the nurse said well, there’s no alarm going off so he must be all right, so my dad went out into the corridor and yelled for someone to send a Respiratory Therapist quick...”**

**“I almost died at that point, there was a time there when I passed out. I was blue and if it wasn’t for my assistant being with me ... the ENT doctor came in and accidentally hit the ventilator and knocked off the tubing so the alarm went off on the ventilator but this doctor didn’t know, she wasn’t from this floor.... I couldn’t breathe now, right, the ventilator’s off, I can’t breathe, so I’m mouthing, I can’t breathe. My assistant’s there and she’s saying to the doctor, she can’t breathe, and the doctor’s saying relax, relax, telling me to relax, and I’m passing out, so my assistant ran and got my nurse and the nurse panicked, didn’t have a clue what to do and she was going around like .... , she ran for the RTs and finally, when I woke up, my bed was surrounded by doctors and nurses... They didn’t realize the ventilator was disconnected and this doctor that came in did not know.”**

**"For three weeks I couldn't talk and they kept saying I just wasn't trying. I had a size 8 trachea and he put in a size 6 and the moment he put it in I spoke, I talked. They had the wrong size but for three weeks they didn't even know that."**

**"If you're ventilator dependent and ... you need to be taken care of, you're not really in any kind of condition to take control. They'll put you in intensive care and they have a mentality there that "they're the doctor: you're the patient and shut up kind of deal."**

#### **6.8.8.4 NEGATIVE PAST EXPERIENCES**

One participant had been so terrified by her 5 year hospitalization as a teenager over 50 years previously that, as an adult, she now just “does her own thing” seeking no healthcare assistance, except in the event of an emergency. Her memories of that long ago initiation to MV still remain vivid.

**“The three days and night routine started. I would not sleep for three days and nights because I couldn't breathe - drifting in and out of a toxic state. During this time I would have to void constantly, defying all rules of "bedpan three times a day only." Fortunately, I would get a severe respiratory infection and have to go back in the iron lung for two weeks. This repeated torture kept up until they gave up and would consent to letting me have the respirator from 3 to 6 a.m. only.**

**The next step was that the doctor would come around at night and lower the pressure so low that you were fighting the machine for every breath. I was constantly being told I had no intestinal fortitude. I would get an orderly to put a sand bag on my chest shall to give a tighter seal which gave a bit more pressure.**

**I was continually being told I wasn't persevering. Every ounce of self-confidence was continually undermined. We were told would only get well if we persevered and the reason we weren't was that we didn't persevere and we would not be acceptable in society or have a future in our condition."**

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**6.8.8.5 LOSS OF CONTROL**

Participants’ sense of loss of control when hospitalized appears to have produced ongoing apprehension and lack of trust.

**"I turn into an idiot when I walk into some hospitals, I don't know why but it happens. I'm a big mouth outside of the hospital and then I get into the hospital and then, it's just not me. I'm not as assertive as I am outside of the hospital. I don't know if that's fear, that's probably what it is. In fact, I don't even go to the hospitals anymore, I just do my own thing. I just follow up in my own way."**

As a result of unsatisfactory experiences, many of the participants in this study recognized their need to be in control of their own healthcare situation as much as possible and had developed strategies for achieving this, such as becoming as educated as possible about their own situation.

**"If you don't take care of yourself nobody can do it for you and doctors have many patients to look after. As an individual I know what I'm feeling and what the conditions I have are, so I do take charge. The good thing with the computer and the Internet is that I can look things out before going to an appointment or a meeting with the doctor."**

**"I would do everything I could to make sure I was in control, at least co-control... if you're going to intubate me and you're going to put me out, you could do anything, you could break my arm, break my ribs, all kinds of stuff."**

**"If you go into a situation like that and have time to prepare, you can force a dialogue and interaction so they can get an understanding of what your pre-existing condition needs are. Then you have a much better chance."**

**"I've always found it's very important to let them know who's in charge if you can, in terms of your own condition... they don't like it when you stand up to them but they respect you when you do, if you can do it in a way that's not offensive."**

Participants unable to avoid going into hospital developed strategies such as taking family members, friends and paid staff to act as their advocate and “protect” them by ensuring they had the ongoing help they needed and their MV equipment was being properly operated and made available

**“I will never go to emerg now without a friend... I always have to tell them, if my friend wasn’t with me, to push on my diaphragm because they just left me alone... I explained to them, I’m on the (phrenic) pacemaker... I need assistance coughing, yadda, yadda, yadda, and they left me alone and then they said, we want to admit you. I said, you’ve got to be kidding. I said hell would freeze over before I’ll be admitted because what are you going to do? I said, you’re going to put me on a floor where I can’t use a call bell and I’ll choke on my phlegm. I said I’ll take my chances at home.”**

In essence, these participants reported that they felt safer relying on their own knowledge of their bodies, on their friends, and on health practitioners whom they trusted rather than they did on hospitals or unknown medical care.

### **6.9.0 What Is Needed To Improve Daily Life**

Participants’ opinions on how daily life could be improved were derived, as one might expect, from the barriers and dissatisfactions they had previously identified.

Improvements in health care, income security, MV technology and accessibility were mentioned most often as the areas where improvement was needed. Some of their comments are as follows:



**6.9.1 Improved Healthcare**

**“A better funded health system with more trained professionals would be my first priority. “**

**“We need time, time is a factor. We need to be able to sit down and talk to our doctors about our whole aspect, not just one, so that they understand all the various factors that impinge upon us and cause things, like the tiredness or what ever, so they’ve got a whole picture.”**

**“Doctors know things I don’t know but in a partnership they can teach me and show me and let me figure it out and give me some trust...”**

**“An online clearinghouse for information on available services and resources specific to respiratory and disability issues would be helpful.”**

**“My problem is in the medicine area where things aren’t covered ... like medications that you might need.”**

**“Improved communication, and co-ordination of exchange of client/patient information between hospitals and govt agencies etc. .... Computer systems don’t blend, don’t communicate with each other... can’t access each other”**

**6.9.2 Greater Respect**

**“Treat us with the same respect and give us the same chance that you would give an able-bodied healthy person.”**

**“...let the person direct their own care, if they know what they’re doing let them do it. Or teach them to know what they’re doing... that’s part of the process too.”**

**6.9.3 Improved MV Technology**

**“Quieter and slower (ventilators), maybe a little bit lighter if it’s possible.”**

**“If it (the ventilator) was more portable or smaller, I’ve always thought it’d be nice to have those little canisters that you see scuba divers use**

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that you could just be able to have something that small if I need to breathe I could just hook it up right away.”

“I was thinking that if they can design it (the ventilator) in ways so that the caregiver won’t be able to change the settings accidentally, for example, add some safety lock or something.”

#### 6.9.4 *Reduced Bureaucracy*

“Less bureaucratic hassle to get services (especially regular ongoing ones).

“ You have to keep filling out your documents, proving who you are, how much money you’ve got, you know, I think the government wastes a lot of money on this stuff”

“...They should consider a guaranteed income rather than through this system because in January, March and April I have to fill out forms for..., forms for home care, forms for..., I get audited by home care, I get audited by the Capital Health Authority for home care stuff, I have to file income tax.

“You name it, it’s about five different things I have to fill out every year and it’s always the same stuff, they seem to be unable to trust you from year to year.”

#### 6.9.5 *Increased Accessibility*

“... (Full accessibility) in shopping malls, stores, private and public sectors. We’re not wanting it in every home that is a private residence but if a company has a (business) geared towards people, they should make it accessible to all people within Ontario, we should have Braille on elevator buttons, we should have ramps to get into buildings.”

#### 6.9.6 *Increased Funding*

“Basically, an increase in funding for services, because we’ve already talked about the housing, it’s the same with the services, whether it be attendant care or transportation.”

**6.9.7 Greater Independence & Control**

“I think technology’s one of the few things that can really help me, like my wheelchair, being able to do things on my own, anything that would provide more independence.”

“I’m trying to investigate a few options to see if I can change the feeding schedules um, right now it’s four times a day. I’m trying to see if I can get it down to three times and it might help. Um, I don’t know quite what to do about driving the wheelchair in the cold and so on. I think if I could afford to have a manual wheelchair to be used for outings that might be helpful.”

“They know things I don’t know but in a partnership they can teach me and show me and let me figure it out and give me some trust...”

“We need time, time is a factor. We need to be able to sit down and talked to our doctors about our whole aspect, not just one, so that they understand all the various factors that impinge upon us and cause things, like the tiredness or what ever, so they’ve got a whole picture.”

**6.10.0 Participants’ Advice****6.10.1 To Consumers<sup>9</sup>**

Participants were asked what advice they would give individuals who are considering the use of mechanical ventilation. Most participants made very similar suggestions, which included self-education, researching the options, choosing your priorities and making an informed decision within the context of one’s own life and needs. The advantages of “doing it early” were suggested as well as the fact that that initiating use does not accelerate life-long dependency.

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<sup>9</sup> The term “Consumers” is a culture specific term which refers in this study to individuals who may be considering or already using Mechanical Ventilation. In Program, Support Services or Healthcare cultures they might otherwise be considered “Clients” or “Patients”.

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Participants were also cautioned that consumers should be prepared for the personal responsibility that comes with using MV.

#### **6.10.1.1 RESEARCH & EDUCATION**

**“...find out as much as possible and talk to people that has had the experience before.”**

**“I think if people are having any type of problems with ventilation, I think they should really really go for what ever it is that helps**

#### **6.10.1.2 ACCEPT RESPONSIBILITY**

**“...be prepared for unexpected things to happen when using ventilation/suction equipment. Personally, I strongly prefer to accept the responsibility and live independently to the greatest degree possible rather than turn the responsibility and control of my life over to an institution.”**

**“...I’ve always found it’s very important to let them know who’s in charge, if you can, in terms of your own condition... they don’t like it when you stand up to them but they respect you when you do it is a way that’s not offensive.”**

#### **6.10.1.3 THE EARLIER THE BETTER**

**“Do it early. The earlier you get onto it the better, the longer you’ll keep your (respiratory) capacity and the more capacity you’ll have to keep.”**

#### **6.10.1.4 FOCUS ON WELLNESS**

**“These days the breathing aides can be put on your chair, make you mobile. You can drive a car with a breathing aid; a lot of people have, so it doesn’t isolate you, so your real problem is yourself.”**

**“I’d say don’t focus on that, focus on well-being and getting out in the community and doing things that you want to do and don’t let it hold you back. That would be my only advice.”**

**“You need to relax and just let it into your life like you do everything else and not consider it as the main thing in your life. It’s just an adjunct on, something that you use.”**

#### **6.10.1.5 CHOOSE YOUR PRIORITIES**

***“I think you have to make decisions about what you want from your life and what priorities you have. If you enjoy life and you want to still be able to function in society then the breathing aide isn’t necessarily going to be a problem.”***

#### **6.10.2 Participants’ Advice to Providers**

Participants’ advice to providers primarily focused on advice to medical practitioners working with individuals who are already using MV or considering MV. In many cases their responses were derived from distressing personal experiences.

**“I have had a doctor refuse to make a visit because I could not tell him how many TEASPOONS of mucus had been suctioned up in the last hour. Two days later, when the doctor did visit, he discovered I had pneumonia.”**

#### **6.10.2.1 SUPPORT MV USER DECISION MAKING**

Participants’ primary message was to support ventilator users (or prospective ventilator users) and enable them to make personally appropriate, informed decisions about initiating use and ongoing medical management.

**“...be aware of quality of life issues and that ventilation does not have as big an impact as they may think it does....”**

**6.10.2.2 IMPROVED EDUCATION ABOUT HOME MV**

Participants believed health care providers must become better educated in order to properly support individuals already using mechanical ventilation. To achieve this, providers need to increase their own knowledge of home use of MV and medical residents and other health care students should be exposed to the benefits and possibilities that use of MV can provide.

**“...get some training, learn to hear an alarm because the alarm is the essential thing that tells you something’s wrong, right? ...and if you’re not breathing they should know how to bag you. They should know a lot of things, they should know everything.”**

**“...they should study the sicknesses around, like the breathing stuff, the ventilator - my family doctor especially.”**

**“More knowledge of vent/respiratory issues and less bullshit is a high priority for doctors and nurses who work with vent users. “**

**6.10.2.3 GREATER RESPECT FOR MV USERS**

**“Just remember that it's an individual, a person, and to help them, always try to help them look forward to bettering the condition...”**

**“...treat us as human beings, individuals, people. We know what we want, what we need, ask us questions, don't impose.”**

## DISCUSSION

There is much debate on the definition of quality of life (11). Dimensions assessed by quality of life instruments range from burden of symptoms to social isolation. We chose to adopt a definition that considered somatic sensation, physical function, emotional state and social interaction (12). Our participants often referred to all four aspects when discussing their quality of life.

Within our society, it is commonly assumed that long term dependence on mechanical ventilation is associated with an unsatisfactory and negative quality of life. This study challenges that assumption, based on information provided by long-term ventilator users about their daily lives and the satisfactions, dissatisfactions, supports and barriers they identified which impact on their perceived quality of life. The participants in this study had generally established a meaningful and often productive life, in spite of ongoing daily challenges related to their disability needs.

The issues perceived as limiting quality of daily life were issues commonly identified by most persons with significant disability who are dependent on public services and programs such as personal support services, assistive devices, accessibility, income security, transportation, accessibility, public acceptance and healthcare. Perceptions of complex bureaucracy, loss of control and choice, inflexibility, and the burden of work involved in constantly scheduling, coordinating and juggling the many inter-related services and personnel required negatively impacted on participants' energy and available time for other more preferred pursuits.

Dependence on long term mechanical ventilation, per se, was generally perceived to be a positive support which enabled participants to lead fulfilling lives within their own

communities. However, additional “ventilator specific” issues which negatively affected quality of life were identified as being related to MV technology inadequacies, to suctioning requirements, and to inadequate healthcare.

The long term MV users in this study were generally satisfied with their overall quality of life and proud of the lives they had established - lives which included family, friends, social activities, volunteer work, homemaking, advocacy, employment and responsibilities; lives made possible by supportive housing and self-managed attendant programs, assistive technology programs, transportation services and supportive healthcare, where it existed.

The suggestions made by participants for improving the health related quality of life for current and prospective long term users of mechanical ventilation are supported by the investigators of this study.

Our recommendations are addressed to all the many individuals, programs and services who are involved in supporting and enhancing the quality of life of individuals who require long term mechanical ventilation and are as follows:



## RECOMMENDATIONS

HRQL appeared to be related far more to control and choice over one's own circumstances than to the presence of absence of disease. Loss of control over the programs, equipment and services, on which one is dependent by virtue of disability, can be reduced through consideration and implementation of the following:

- Wherever possible, greater consumer education and involvement in decisions and planning regarding type of ventilation and MV equipment. This includes information about health outcomes, implications for life style and personal responsibility, opportunities for research and networking with experienced MV peers and opportunities for equipment trial and choice.
- Opportunities for direct involvement with MV equipment manufacturers, so as to encourage development of MV equipment which enhances opportunities for an improved quality of life. (e.g. smaller, quieter, more efficient).
- Improved education of physicians and other healthcare providers, which includes increased awareness and understanding of the positive quality of life of MV users who live and participate in the community as well as the need to holistically understand and address the inter-related underlying disability needs in conjunction with respiratory issues. Physicians and other healthcare providers need to understanding the negative aspects of home ventilation such as the limitations associated with suctioning. This also includes “respect” for the

knowledge and experience of many long term MV users who value and seek to obtain a “partnership” relationship with their physicians.

- Improved healthcare, which includes access to general practitioners who understand hypoventilation and MV and who are able to provide the time needed. It also includes provision of the resources required to support an MV user during a health care crisis or when hospitalized.
- Enhanced opportunities for MV users to live supported lives within their own communities. This includes continued opportunities for self-directed attendant programs for those MV users who are able to manage this option, as well as accessible Supportive Housing Programs with increased staff resources so as to enable individuals with unpredictable suctioning requirements to be accompanied into the community for activities related to maintaining an optimal quality of life.
- Support and relief for family caregivers, many of whom are now aging, as well as preparation and planning for future resource availability when they are no longer able to provide assistance.
- Continuation of valued public supportive programs, such as provincial assistive devices programs, home ventilation programs, income security, public transportation, supportive housing and self-managed attendant programs - with serious consideration being given to improvements and enhancements, as identified by persons who are dependant on such programs.

- Reduction and streamlining of bureaucratic system complexities and inefficiencies which increase the “burden of work” for consumers requiring such services. Although greater choice and control over services received necessarily involves increased responsibility and work (e.g. directly funded, self-managed attendant programs) these programs could be reviewed with a view to evaluating the possibility of shared or reduced administrative requirements.

As persons with significant physical disabilities have often said, it isn't the disability or the need to be mechanically ventilated which is the problem. Rather, it's the services and resources on which your disability renders you dependent.

**“Since I was first ventilated I was determined to go on living my life the way I had been and so I didn't really let it affect my lifestyle that much and in the long run it really hasn't other than the housing issues and the equipment and the attendants ....”**

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# APPENDIX 1

## Participant Interview Guide



## 11.1.0 Participant Interview Guide

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*Revised June 12, 2001*

**This study is about issues that affect people’s satisfaction with their quality of life when they are using mechanical ventilation. I’d like you to keep that in mind as we go through the questions, although I am interested in hearing all of your ideas and experiences in terms of how satisfied you are with different aspects of your life.**

1. Please tell me about your life at present in terms of your day-to-day activities including things like work and recreation, your social life, your ability to get out and about.
2. What are you most satisfied with in your life at present?
3. What are you least satisfied with in your life at present?
4. What factors do you think have the most impact on your satisfaction with your life?
5. What factors do you think have the most impact on your dissatisfaction with your life?
6. How do you deal with these factors?
7. What do you think is needed to make it easier for you to get what you want in your day-to-day life?
8. Have things changed for you over time as you have adjusted to living with mechanical ventilation?

(The next 2 questions might require some clarification from the interviewer in order to separate out issues related to the disability from issues related to using MV.)

9. What do you think has contributed the most to your adjustment to living with a disability?
10. What do you think has contributed the most to your adjustment to using mechanical ventilation?
11. What do you think affects your day-to-day life the most? Having a disability or having to use mechanical ventilation? Is there a difference?

12. What advice would you offer to people who are new to living with mechanical ventilation?
13. What advice would you offer to medical practitioners who work or will work with people who use mechanical ventilation?
14. Is there anything else you think it would be useful for us to know about quality of life for people using mechanical ventilation?

# APPENDIX 2

## Participant Information

&

## Consent Form

## 11.2.0 Participant Information and Informed Consent

### 1. Introduction

The purpose of this research project is to talk to individuals who are using mechanical ventilation in order to learn about their perspectives on health-related quality of life issues. Our primary goal is to gather and disseminate information about living with mechanical ventilation in order to help consumers, health services providers and policy makers become more informed about the experiences and concerns associated with home mechanical ventilation.

The investigation team includes the following:

Mark Tonack	West Park Healthcare Centre
Dina Brooks	West Park Healthcare Centre, University of Toronto
Audrey King	Consumer Advocate, Ventilator User
Helen Simson	Project Coordinator
Maria Gould	Interviewer

### 2. Process

Over a period of approximately twelve months, each person who volunteers to take part in this study will be asked to participate in two different ways:

#### a) Personal interview

This first step involves a face-to-face interview with our interviewer. She will ask you questions about:

- your experiences with using home mechanical ventilation;
- any difficulties and/or advantages that you encountered;
- any recommendations that you think would improve the experience of using mechanical ventilation;
- Your perceptions of how using mechanical ventilation affects or enhances your quality of life.

The interview will take about 1½ to 2 hours. The interviewer can meet with you in any place that is convenient for you, including your home or West Park Healthcare Centre.

The interview will be tape recorded, and afterward will be typed word-for-word from the tape. At the end of the project, this tape recording will be destroyed, but the typed copy will be kept as a permanent record. The typed copy will not include your name or any personal identification.

**b) Reviewing the research summary**

This step involves reading a brief report on the preliminary findings from the interviews. We want to ensure that the research report correctly summarizes the information that has been shared with us in the interviews. We will ask you to review what we have written about your interview and let us know what you think of it – did we get it right, or do we need to make corrections? You may choose to give us your comments in any way you wish – a written note, a telephone conversation or a face-to-face meeting. Completing this task, as with every other part of this process, is completely up to you.

**3. Discomforts**

There are no major risks associated with participating in this study. However, it is possible that you may feel uncomfortable talking about yourself during the interview. You might feel that you disclosed more information about your personal life than you had intended to share. Or you may feel discouraged or saddened about some of your experiences after the interview is over.

If you do feel troubled after the interview or at any time during the research process, you can contact either Maria Gould, the interviewer, or Helen Simson, the project coordinator, for advice. They can be reached through confidential phone lines: in Toronto call 416-243-3768. We have a toll free number for long distance callers: 1-866-618-2891.

**4. Benefits**

We hope that participating in this research project will be a positive learning experience for everyone involved. As a participant, you will have the opportunity to:

Voice your concerns, your ideas and your opinions about what you think is important regarding quality of life

Assist the research team in improving understanding of the complex issues associated with life with mechanical ventilation

**Learn first-hand how researchers work and what is involved in an important type of study called qualitative, collaborative research (this project fits within that category). Know that your contributions may help to improve services available to other individuals using home mechanical ventilation in the future.**

**5. Confidentiality**

Because you will be sharing personal information about your life, we will take the following precautions to protect your confidentiality:

- The tape recording of your interview will be destroyed at the end of the project
- The typed notes from your interview will not include your name or any details that would identify who you are

- Your name or identifying personal information will not be used in the final report or any publications about the study
- All information pertaining to this study will be stored in a safe, secure and locked location at West Park Healthcare Centre.

### **6. Voluntary Participation**

Your participation in this project is strictly voluntary. You are able to withdraw at any time before, during, or after the interview with no penalty. If you should decline to participate it will not affect any services you receive from West Park Healthcare Centre.

You can choose not to answer any of the interview questions, as you see fit.

### **7. Expenses**

We will reimburse you for any expenses directly related to your participation in this study. This means that we will pay your transportation costs and salary for any attendant services required. If you have any questions about whether certain expenses can be covered, please discuss this with Maria.

### **Project Completion**

This research project will be completed in spring 2002. After the project is over:

- You will receive a copy of the research report,
- You will receive a \$50.00 honorarium in recognition of your contribution,
- The tape recording of your interview will be destroyed,
- The typed notes from your interview will be kept in a safe locked place at West Park Healthcare Centre.

### **Questions and Concerns**

If you have any questions or concerns, please contact either Maria Gould or Helen Simson at the numbers listed above.

## Participant Consent Form

I have been invited to participate in a research study that looks at the experiences of individuals using home mechanical ventilation. My participation will involve one personal interview (approximately 1½ to 2 hours long), and reviewing what the researchers write about what I have told them. Also, if I choose, I may provide feedback on the findings of the project to the investigation team.

The researcher whose name appears below has explained the study to me. I have also read the information sheet that the researcher has given me. I understand the possible risks and discomforts, and know that I can stop being a part of this study at any time without penalty. I also understand that my participation is confidential and that my identity will not be apparent in the final study results or in any documents kept by West Park Healthcare Centre.

**I agree to be a part of this study. I also agree to have my interview tape-recorded.** I understand that at the end of the research project these tapes will be erased, and that until that time the researcher will keep them in a safe place. **I also understand that after the study ends, West Park Healthcare Centre will keep the notes from my interview in a safe and locked place.**

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Your name

---

Your signature

---

Researcher's name

---

Researcher's signature

---

Date

# APPENDIX 3

## Participant Demographic Form



## 11.3.0 Participant Demographic Form

### Pre-interview Demographic Sheet

Initials: \_\_\_\_\_

Date \_\_\_\_\_

Location: \_\_\_\_\_

Interviewer: \_\_\_\_\_

1. Date of Birth: \_\_\_\_\_

2. Gender:  female       male

3. Do you have strong ties to a particular cultural or ethnic community? If so could you describe this community (or communities) for me?

4. Can you tell me about your education background?

5. How do you typically spend your day?  
(Paid work, voluntary work, family/domestic responsibilities, social/recreational)

6. How would you describe your disability?

When were you originally diagnosed?

In addition to your main diagnosis, do you have any other conditions or diseases?



# APPENDIX 4

## Feedback Session

## FEEDBACK SESSION

### 11.4.1 Feedback Session Letter

April 17, 2002

**Re: Study on Ventilator Users' Perspectives on the Important Elements of**

#### **Health-Related Quality of Life**

Mark Tonack, Senior Research Officer at the Toronto Rehabilitation Institute, Lyndhurst Centre; Dr. Dina Brooks, Research Associate at West Park Healthcare Centre and Assistant Professor, Department of Physical Therapy, University of Toronto; Dr. Roger Goldstein, Professor of Medicine, University of Toronto; and Audrey King, Consumer Advocate and MV user. The team also includes an interviewer, Maria Gould, and project coordinator, Helen Simson

**Dear**

**We would like to thank you again for participating in this study. Your feedback was extremely valuable in gaining insight into the perspectives of ventilator users. We are pleased to send you a preliminary summary of the key findings from this study. We would like to receive your feedback on the issues we have identified as we begin to analyze the data. Your feedback will help to ensure that our analysis of the data is valid and consistent with what interview participants told us. You can provide feedback in two ways:**

-you can use the attached Feedback Questionnaire to tell us what you think about the summary;

-if you live in the Greater Toronto Area you can also join the project team for an in-person feedback session that will take place from **7 to 9 p.m.** on **Wednesday May 8** at the **Lyndhurst Centre** of the Toronto Rehabilitation Institute, in **Lecture Room A**. The Lyndhurst Centre is located at 520 Sutherland Drive.

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**Please be assured that any feedback you provide will not be used in any way that will identify you. Also, please keep in mind that this summary provides a preliminary review of the data: the final report for the study will provide much more detail.**

You can use the stamped envelope that is included in this mailing to return your Feedback Questionnaire (feel free to add more pages if you wish). We would appreciate receiving your questionnaire by **Friday May 5<sup>th</sup>**. If you prefer, you can e-mail your feedback to the team: the address is [h.simson@sympatico.ca](mailto:h.simson@sympatico.ca).

If you wish to participate in the in-person feedback session at the Lyndhurst Centre in Toronto, please let us know by **Wednesday May 1<sup>st</sup>** for planning purposes. You are welcome to bring someone with you (for example a family member or attendant) but we need to know this as well by May 1<sup>st</sup>. We will provide food and beverages at the session, and will have attendants who are familiar with respiratory needs available. You can RSVP either by leaving a message at **416-243-3768** or, if you live outside of the 416 area, at our toll-free<sup>1</sup> number **1-866-618-2891**. Or, you can send an e-mail to [h.simson@sympatico.ca](mailto:h.simson@sympatico.ca). When you RSVP, please tell us if you will be attending, whether you will be bringing someone with you, and whether you require assistance from our attendants. The project team will reimburse attendees for the cost of transportation to and from the feedback session and for any personal care costs if you bring your own support person.

On behalf of the team, thank you for all of the assistance you have provided to this important study. We appreciate your time and your thoughtful input, and we look forward to receiving your feedback on the questionnaire and, for those participants in the Toronto area, we hope to see you at the feedback session on May 8<sup>th</sup>.

Sincerely,

Dina Brooks



## **Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life**

Funded by a small grant from The GINI Research Fund, this Canadian research project is led by a team comprising Mark Tonack, Senior Research Officer at the Toronto Rehabilitation Institute, Lyndhurst Centre; Dr. Dina Brooks, Research Associate at West Park Healthcare Centre and Assistant Professor, Department of Physical Therapy, University of Toronto; Dr. Roger Goldstein, Professor of Medicine, University of Toronto; and Audrey King, Consumer Advocate and MV user. The team also includes an interviewer, Maria Gould, and project coordinator, Helen Simson

### **11.4.3 Preliminary Summary of Key Findings**

#### **April 2002**

Twenty-six individuals participated in this research study. Interviewing took place in the Greater Toronto and Edmonton areas. This summary provides a preliminary overview of the main issues that are emerging as we go through the process of completing data analysis. All participants used some form of MV (mechanical ventilation) on a daily basis as well as a wheelchair or scooter. Sixteen participants were male and 10 were females, ranging in age from 23 to 66 years, with the average age being 44 years. Use of MV was related to diagnoses of polio, muscular dystrophy, spinal muscular atrophy and spinal cord injury

#### **KEY FINDINGS:**

##### **✓ Mechanical Ventilation is Regarded as a Positive Benefit in Daily Life**

**Interview participants described their use of mechanical ventilation (MV) as a positive aspect of their lives. They found that its benefits included increased energy and improved ability to sleep at night. Participants used invasive ventilation via tracheotomy, non-invasive ventilation via mask or nasal pillows as well as internal diaphragmatic pacers**

**While participants' perceptions of the use of MV were primarily positive, several areas of dissatisfaction associated with the technology were identified: some participants found the size of their MV equipment cumbersome, especially for traveling out of the house; some participants found that the equipment was noisy, especially at night.**

**Another area of concern associated with using MV for some participants centered around suctioning. Some participants found that their need for suctioning interfered with their independence because they did not have adequate and appropriate support persons to accompany them out of the house. Suctioning equipment was also regarded as cumbersome by some participants and, therefore, a further barrier to getting out of the house.**

**✓ MV Equipment Programs are Regarded as Effective**

Interview participants were almost unanimous in their perceptions that the provincial services that supplied their MV equipment were effective in providing, maintaining and replacing equipment as required. Interestingly, some participants did not appear to know much about the program in their province (for example its name) but found that their equipment needs were reliably supported.

Some participants expressed a desire to have more choice over the type of equipment they had (for example, being able to choose smaller or more portable equipment). Many participants reported that they had two ventilators, one for backup in case of equipment breakdown.

**✓ Quality of Life is Regarded Positively**

Participants' daily life experiences spanned a rich and broad spectrum of activities, vocations and involvements. Some worked outside of the home or free-lanced from home, some operated their own businesses, some participants were engaged in volunteering activities, some were engaged in post secondary education and some were parents and homemakers. Some traveled, participated in community boards and committees and in some cases provided care for other family members.

All but two of the participants required support with activities of daily living (ADL). They received support from paid attendants and personal support workers, family and friends. Participants felt that support from family and friends were a significant factor in their satisfaction in life. They were generally satisfied with the quality of support they received from paid support workers.

**✓ Physical, Social and Economic Barriers Are Identified**

Participants reported that inaccessible physical environments restricted their ability to engage in activities outside of the home. Inadequate financial support was also reported by some as negatively affecting quality of life. When asked whether their disability or their use of MV most affected their quality of life, participants identified the barriers that constrained their ability to live independently as the most significant. MV was described as enhancing quality of life, while the social and economic restrictions associated with having a disability had a negative impact.

Para-transport systems were frequently identified as problematic in terms of inflexible scheduling and the time required for travelling. Some participants felt that they were discouraged from participating in paid employment because they would lose funding for support with ADL and for medications if they earned an income. Participants described many personal strategies for dealing with and overcoming the barriers they encountered in their lives.



✓ **Advocacy is Important**

Participants reported that they themselves and/or family members engaged in advocacy to create, influence and change the supports and services they required and used. Some participants were involved in the creation of the supportive housing in which they lived. Others advocated for the support services they required to live independently. In some cases, family members advocated for participants in critical health situations. Advocacy emerged as a significant theme in many of the interviews.

✓ **Health Care Providers Need to be More Knowledgeable About MV**

Participants described numerous incidents in which health care providers lacked appropriate understanding of long-term MV. Visits to hospitals for conditions not related to respiration were described as particularly problematic: some participants reported that they avoided going to hospital or deferred medical treatments because they did not feel that they would be safe in terms of ventilation. Others reported that they always had family members or paid support workers with them in hospital in order to ensure that their MV equipment was properly operated. While participants regarded MV as an assistive device, some reported that medical practitioners described it as life support, an interesting discrepancy in how ventilatory equipment is perceived

✓ **Consumers Who Require Support with Breathing Should Consider the Benefits of MV**

When asked what advice they would offer to consumers who may be considering the use of long-term MV, participants felt that consumers should inform themselves about the potential benefits of MV. They also felt that consumers should be provided with information about the range of MV options that are available.

✓ **Personal Health is Regarded as Good**

When asked to rate their perceptions of their own health on a scale of 1 to 10 ('1' being the lowest and '10' being the highest), participants were generally very positive about their health. The average reported on the scale was 7.5. The lowest score was 4 and the highest was 12 (which was off our scale!).

# APPENDIX 5

## Participant Demographics

## 12.5.0 Participant Demographics

Int. #	Sex	Age	Ethnicity	Diagnosis	Other Diag	When Diag	Type of MV	When Intro'd	Why Intro'd	Hrs MV/Day	How MV	Work	Education	Residence	Support	Providers	Health
Pilot 1	F	65	Cauc	Polio	NA	Age 13	PLV 100	1949	Acute Resp	24	Day-tube	Self Empl	Post Sec	W Husband	ADL	PSWs	10
											Night-Mask						Husband
Pilot 2	M	39	Cauc	SCI	NA	Age 20	Pacers	1982	Injury	24		Self Empl	Secondary	SLU	ADL	PSWs	8
																	Family Volunteers
Int 1	F	62	Cauc	SMA	NA	Age 12	BiPap 30	1991	Poor Health	18	Nasal Mask	Retired	Grade 9	W Husband	ADL	PSWs	4
																	Husband
Int 2	F	68	N/A	Polio	NA	Age 7	PLV 100	1989	Acute Resp	At Night	Trach	Volunteer	Secondary	SLU	ADL	PSWs	8
Int 3	M	40	N/A	DMD	Cardiomyopathy	Age 10	PLV 100	1983	Emergency	24	Trach	Volunteer ?	Post Sec	W Parents	ADL	PSWs	7
Int 5	F	64	N/A	SMA		Age 10	PLV 100	1979		24	Trach	Homemkr	Secondary	W Husband	ADL	PSWs	10
Int 6	M	23	N/A	Trans Myelitis	NA	Age 30	LP 6	1996	Paralysis	In Bed	Trach		In Yr 1 BA	SLU	ADL	PSWs	7
Int 7	M	35	N/A	CP		Age 2	PLV 100	1995	Acute Resp	Night	Trach	Volunteer	Post Sec	W Mother	ADL	PSWs	8
Int 8	M	27	Portuguese	MD	NA	Age 8	LP 6	1999	Acute Resp	At Night	Trach		Secondary	W Family	Personal	PSWs	10
																	Parents
Int 9	F	52	N/A	SMA	Sleep Apnea	Age 1	Bi Pap	1987	Sleepiness	At Night	Nasal Mask	Self Empl	M.A.	Alone	ADL	PSWs	8
Int 10	M	38	Italian	MD	NA	Age 3	PLV 100	1987	Pneumonia	21	Trach		Post Sec	W Family	ADL	PSWs	7.5
																	Parents
Int 11	M	32	N/A	MD	NA		LP 10	1996	Weakness	24	Trach		Post	W Family	ADL	PSW	7

Int 12	M	28	N/A	SCI	Scoliosis	At Birth	LP 10	1988	s Cardiac Arst	At Night	Trach		Sec Second ary	Foster Prnts	ADL	Nurse PSWs	7
Int 13	F	46	N/A	SCI	NA	Age 19	Pacers	1973	Injury			Volunteer	Second ary	SLU	ADL	PSWs	10
Int 14	M	40	N/A	SMA	NA	Age 2	PV 2801	1990	Acute Resp	At Night	Trach	Volunteer	Second ary	W Family	ADL	PSWs	10
Int 15	M	45	Mace- donia	MD	NA	Age 7	LP 20	1983	Pneumon ia	24	Trach		Some Sec	Hospital	ADL	Med Staff	8
Int 16	M	42	N/A	ALS	NA	Age 21	Lp10	1998	Pneumon ia	At Night	Trach	On LTD	In MBA	Alone	ADL	PSW Nurse	8.5
Int 17	M	31	Malte se	SCI	NA	Age 8	PLV 100	1978	Injury	At Night	Trach	Self Empl	Post Sec	W Parents	ADL		10
Int 19	F	29	N/A	SMA	Heart	Age 1	LP 6	1989	Sleep Apnea	At Night	Trach	Childcare	Second ary	Mom/ Hsbnd	ADL	Mom/Hs bnd	No Opinion
Int 20	F	38	N/A	SMA	Sleep Apnea	Age 10	Bi Pap	1993	Acute Resp	At Night	Nasal Pillow	Self Empl	Post Sec	W Family	ADL	PSWs	8
Int 21	F	53	N/A	Polio		Age 5	LP 6	1990	Sleep Probs	Day Night	& Mouth Piece	Retired	Post Sec	W Family	ADL	PSWs	10
Int 22	M	62	N/A	Polio		Age 15	PLV 100	1988		Nights	Nasal Mask	On LTD	Post Sec	W Wife	None Req'd		6
Int 23	M	55	N/A	Polio		Age 13	LP6	1960	Polio	Nights	Trach	Supervis or	Post Sec	W Family	ADL	Orderlie s	8
Int 24	F	60	N/A	Polio	Asthma		PLV 100	1990	Sleep Probs	Nights	Mask/Mth Pc	Advocate	Post Sec	SLU	ADL	PSWs	5
Int 25	M	56	N/A	Polio		Age 9	LP6	1955	Polio	Nights	Mouth Piece	Administr ator	Second ary	W Family	ADL	PSWs	10
Int 26	M	25	N/A	MD	Scoliosis	Age 11	LP6	1993	Acute Resp	Nights	Trach	Web Designr	Second ary	SLU	ADL	PSWs	8.5