

Daily Living With Distress and Enrichment: The Moral Experience of Families With Ventilator-Assisted Children at Home

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ABSTRACT

OBJECTIVE. The growing shift toward home care services assumes that “being home is good” and that this is the most desirable option. Although ethical issues in medical decision-making have been examined in numerous contexts, home care decisions for technology-dependent children and the moral dilemmas that this population confronts remain virtually unknown. This study explored the moral dimension of family experience through detailed accounts of life with a child who requires assisted ventilation at home. This study involved an examination of moral phenomena inherent in (1) the individual experiences of the ventilator-assisted child, siblings, and parents and (2) everyday family life as a whole.

METHODS. A qualitative method based on Richard Zaner's interpretive framework was selected for this study. The population of interest for this study was the families of children who are supported by a ventilator or a positive-pressure device at home. Twelve families (38 family members) were recruited through the Quebec Program for Home Ventilatory Assistance. Children in the study population fell into 4 diagnostic groups: (1) abnormal ventilatory control (eg, central hypoventilation syndrome), (2) neuromuscular disorders, (3) spina bifida, and (4) craniofacial or airway abnormalities resulting in upper airway obstruction. All 4 of these diagnostic groups were included in this study. Among the 12 children recruited, 4 received ventilation via tracheostomies, and 8 received ventilation with face masks. All of the latter received ventilation only at night, except for 1 child, who received ventilation 24 hours a day. Family moral experiences were investigated using semistructured interviews and fieldwork observations conducted in the families' homes.

RESULTS. Data analysis identified 6 principal themes. The themes raised by families whose children received ventilation invasively via a tracheostomy were not systematically different or more distressed than were families of children with face masks. The principal themes were (1) confronting parental responsibility: parental responsibility was described as stressful and sometimes overwhelming. Parents

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Key Words

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Abbreviation

HCP—health care professional

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needed to devote extraordinary care and attention to their children's needs. They struggled with the significant emotional strain, physical and psychological dependence of the child, impact on family relationships, living with the daily threat of death, and feeling that there was "no free choice" in the matter: they could not have chosen to let their child die. (2) Seeking normality: all of the families devoted significant efforts toward normalizing their experiences. They created common routines so that their lives could resemble those of "normal" families. These efforts seemed motivated by a fundamental striving for a stable family and home life. This "striving for stability" was sometimes undermined by limitations in family finances, family cohesion, and unpredictability of the child's condition. (3) Conflicting social values: families were offended by the reactions that they faced in their everyday community. They believe that the child's life is devalued, frequently referred to as a life not worth maintaining. They felt like strangers in their own communities, sometimes needing to seclude themselves within their homes. (4) Living in isolation: families reported a deep sense of isolation. In light of the complex medical needs of these children, neither the extended families nor the medical system could support the families' respite needs. (5) What about the voice of the child? The children in this study (patients and siblings) were generally silent when asked to talk about their experience. Some children described their ventilators as good things. They helped them breathe and feel better. Some siblings expressed resentment toward the increased attention that their ventilated sibling was receiving. (6) Questioning the moral order: most families questioned the "moral order" of their lives. They contemplated how "good things" and "bad things" are determined in their world. Parents described their life as a very unfair situation, yet there was nothing that they could do about it. Finally, an overarching phenomenon that best characterizes these families' experiences was identified: daily living with distress and enrichment. Virtually every aspect of the lives of these families was highly complicated and frequently overwhelming. An immediate interpretation of these findings is that families should be fully informed of the demands and hardships that would await them, encouraging parents perhaps to decide otherwise. This would be but a partial reading of the findings, because despite the enormous difficulties described by these families, they also reported deep enrichments and rewarding experiences that they could not imagine living without. Life with a child who requires assisted ventilation at home involves living every day with a complex tension between the distresses and enrichments that arise out of this experience. The conundrum inherent in this situation is that there are no simple means for reconciling this tension. This irreconcilability is particularly stressful for these families. Having their child permanently institutionalized or "discon-

nected" from ventilation (and life) would eliminate both the distresses and the enrichments. These options are outside the realm of what these families could live with, aside from the 1 family whose child is now permanently hospitalized, at a tremendous cost of guilt to the family.

CONCLUSIONS. These findings make important contributions by (1) advancing our understanding of the moral experiences of this group of families; (2) speaking to the larger context of other technology-dependent children who require home care; (3) relating home care experiences to neonatal, critical care, and other hospital services, suggesting that these settings examine their approaches to this population that may impose preventable burdens on the lives of these children and their families; and (4) examining a moral problem with an empirical method. Such problems are typically investigated through conceptual analyses, without directly examining lived experience. These findings advance our thinking about how we ought to care for these children, through a better understanding of what it is like to care for them and the corresponding major distresses and rewarding enrichments. These findings call for an increased sensitization to the needs of this population among staff in critical care, acute, and community settings. Integrated community support services are required to help counter the significant distress endured by these families. Additional research is required to examine the experience of other families who have decided either not to bring home their child who requires ventilation or withdraw ventilation and let the child die.

THE GROWING SHIFT toward home care services assumes that "being home is good" and that this is the most desirable option. Although ethical issues in medical decision-making have been examined in numerous contexts, home care decisions for technology-dependent children and the moral dilemmas that this population confronts remain virtually unknown.¹⁻⁴ This study explored the moral dimension of family experience through detailed accounts of life with a child who requires assisted ventilation at home. For the purposes of this study, "moral" refers to whatever phenomena the participants themselves considered "right or wrong." This study involved an examination of moral phenomena inherent in (1) the individual experiences of the ventilator-assisted child, siblings, and parents and (2) everyday family life as a whole.

There are no known studies of the moral experience of families with ventilator-assisted children at home. However, the literature suggests that caring for a child with complex needs has for the family important social, psychological, physical, and financial consequences that can give rise to significant moral dilemmas. For example, parents may experience a moral tension between want-

ing to provide their child all of the benefits of being cared for at home while struggling with all of the personal and familial strains that this implies.

Teague et al⁵ concluded that the demands of technology-dependent children could isolate families from sources of support. Cohen⁶ determined that the nature, quality, and range of these families' social interactions decreased over time. A United Kingdom study of home care for technology-dependent children reported that services were underdeveloped and poorly planned and, consequently, insufficiently supportive.⁷

The constant demands associated with caregiving can adversely affect the physical⁸ and mental⁹ health of caregivers. Financial issues are a common concern and source of strain for these families.^{6,10} The constraint and inhibition of normal family functioning can have a negative impact on the family's quality of life.¹¹⁻¹³ Kuster et al¹⁴ reported that the high demands of caring for a ventilator-assisted child diminishes the health-promoting activities of mothers. Also, interacting with health professionals can serve as a source of stress for parents of ventilator-dependent children.^{15,16}

A very small body of literature has examined moral issues for children who require complex home care. Brinchmann's¹⁷ study of parental experiences with newborns with severe disabilities reported that these children were highly dependent on their parents, who in turn were caught in a moral bind between both loving and hating their children. The home can come to feel like a prison for these parents, from which it is impossible to escape. In a study of the transition of technology-dependent children from hospital to home, Cohen¹⁸ highlighted that ethical issues may be concealed by dominant cultural values, institutional policies, clinical standards, historical precedents, and legal regulations.

Davies¹⁹ documented the dilemmas involved in the decision to support 1 specific child with motor and sensory neuropathy at home with mechanical ventilation. He argued for the importance of supporting home care in relieving the "unmeasurable" degree of misery that such children encounter in hospitals, despite the significant financial costs that ensue. Noddings²⁰ presented a conceptual analysis of parental provision of high-tech home care that challenges the prevalent view that parents have a moral obligation to care for their children. She asserts that such families require help rather than legal coercion or pressure to take their children home. Battle²¹ called for physician and societal advocacy for the provision of comprehensive care for children and families who survive technologic care.

In our own pilot study of the experiences of families who care for ventilator-dependent children at home, we identified moral dilemmas that, for the most part, are neither verbalized nor addressed.²² It was particularly remarkable that families did not readily speak of such phenomena in explicitly moral terms. Families did not

label moral dilemmas (ie, concerns about doing the right or wrong thing) as ethical or moral issues.

The small number of studies conducted to date raises numerous concerns about this population. However, much of the research has not focused particularly on families who care for ventilator-assisted children. Virtually no empirical research has examined the moral experience of these families. The objective of this study was to uncover the moral experience of families with a child who requires assisted ventilation at home.

METHODS

A qualitative method based on Zaner's²³⁻²⁵ interpretive framework was selected for this study. Interpretivism is premised on a conception of human experience wherein moral life is rooted in the context within which it is lived. This approach is textured by a dialectic tension between the appeal to similarities (pattern recognition) and the need to be attentive and responsive to the unique features of every individual case. Every encounter is interpreted in terms of acquired understandings, shaped by previous experiences and the cultural system within which such experiences are lived. An interpretive approach seeks to understand human experience through thick contextual description, complemented with comparative analyses that elucidate significant patterns and similarities across cases. The operationalization of this method for the purposes of this study is explicated in the data-collection and -analysis procedures described below.

Setting and Participants

This study was conducted in Quebec, Canada, where physician services (hospital and community) and all hospital services are state funded. However, nonphysician community services are not necessarily government subsidized. Funding for such services varies from province to province.

In Quebec, local community health centers provide most front-line community health care. These facilities have the mandate to assist people at home with a wide range of medical needs. Some support services and financial aid are available to families who require more services than can be maximally provided by the local community health centers. In cases of complex care in the home, these resources fall short of providing coverage for the 24-hour care that may be required and do not compensate for decreased income for days of work lost, among other uncompensated costs.

The population of interest for this study was the families of children who are supported by a ventilator or a positive-pressure device at home. Participants were recruited through the Quebec Program for Home Ventilatory Assistance based at the Montreal Chest Institute, McGill University Health Centre. Since its inception in 2001, the Quebec Program for Home Ventilatory Assistance has accepted 61 pediatric patients. On average,

there are 7 to 10 new referrals each year, with an average of 5 cases closed per year, mainly as a result of patients being transferred to the adult sector, improvement in their condition after corrective surgery or other treatments, or death. The majority (84%) of these patients receive ventilation via a face mask; the remaining group (16%) have tracheostomies.

Thirty-nine children were enrolled in this program at the time of data collection. Families who met the following criteria were included: (1) caring for a child at home with assisted ventilation for at least 2 to 5 years, (2) had not participated in the pilot study, and (3) able to speak English or French. Fifteen families met the inclusion criteria. Most of the remaining families' children had not been receiving ventilation for the required minimum of 2 years. Three families were unable to participate because of significant psychosocial issues in the home. One family who initially agreed to participate subsequently declined. Thus, 11 of these families were recruited.

Two children who required long-term assisted ventilation and were predominantly hospitalized were also invited to participate. The families of these children were unable to care for them at home, except for occasional home passes on selected weekends. These families could provide some insight into the dilemmas faced by families who choose not to care for their child at home. One child, an adolescent, refused to participate, stating that he did not want to discuss these matters. The second child's family was interviewed at home. In total, 12 families were recruited, resulting in 38 individual participants, that is, patients, parents, and siblings (Table 1).

Children in the study population were in 5 diagnostic groups: those with (1) abnormal ventilatory control, such as central hypoventilation syndrome (a group afflicted from birth yet virtually unlimited in intellectual and motor development), (2) neuromuscular disorders that require ventilatory support as a result of respiratory muscle weakness (a group that faces a primarily degenerative condition with significant progressive diminution of motor functions), (3) spina bifida (a stable disease that

can limit the neuromuscular regulation of breathing), and (4) craniofacial or airway abnormalities resulting in upper airway obstruction (a group that requires a series of surgical procedures over time that may or may not result in the eventual elimination of the need for assisted ventilation). All 4 of these diagnostic groups were included as this study aimed to identify central phenomena that characterized the experiences of families of ventilator-assisted children in general. Among these 12 children, 4 received ventilation via tracheostomies, and 8 received ventilation with face masks. All of the latter received ventilation only at night, except for 1 child, who received ventilation 24 hours a day.

Recruitment Procedure

Families who met the inclusion criteria were asked whether they would agree to be contacted by a member of the research team. The study then was explained to families who accepted. The interviewers were clearly differentiated from the care providers in the home ventilation program to reassure participants that their decision to participate would not affect the care that they received. Parents who agreed for their families to participate were asked to sign a written consent form. Children were also provided an explanation of the study. They were asked to provide verbal assent witnessed by the parents and the research nurse.

An interview in the home with all family members was arranged. All interviews were audiotaped. Four families were asked for additional consent to detailed fieldwork observations. The remaining 8 families were not asked for such consent because the interviewers judged that this would be too burdensome for these families, based on the difficulties that they exhibited in making time for the interview. Three families consented. Only 1 observation session was conducted for each family. A fourth family had also consented but was subsequently unable to find the required time. The study was approved by the Montreal Children's Hospital Research Ethics Board.

TABLE 1 Description of Study Participants

Age of Child, y	Years on Assisted Ventilation	Diagnosis	Interview Participants
19	2	Muscular dystrophy	Mother, father, child, and sibling
16	4	Myopathy	Mother, father, child, and sibling
5	3	Myopathy	Mother, father, and child
19	3	Spina bifida	Mother, child, and sibling
19	8	Spina bifida	Father and child
13	13	Central hypoventilation syndrome	Mother and child
15	15	Central hypoventilation syndrome	Mother, father, child, and sibling
8	5	Central hypoventilation syndrome	Mother, father, child, and sibling
18	2	Obstructive apnea	Mother, father, child, and 3 siblings
10	10	Myopathy	Mother and sibling
1.8	1.8	Central hypoventilation syndrome	Mother and child
14	4	Spinal amyotrophy	Mother and child

Data-Collection Procedures

Demographic and clinical data were collected from the patient's chart by the research nurse. Family moral experiences were explored using semistructured interviews, first with the entire family, followed immediately by interviews with individual family members. Many families preferred expressing their views as a group only. Several families first were interviewed as a group, and then parents were interviewed without the children present. Participants were asked to describe their experiences of living with a ventilator-assisted child. They were asked to talk about situations for which they felt a concern about whether they were doing the "right or wrong thing." Sample family questions included, "What is it like to have (child's name) at home with the equipment s/he needs to help him/her breathe?" "What kinds of things bring pleasure to your family's life?" "What kinds of things bring pain or distress to your family's life?" Sample parent questions included, "Think back to the time when the decision was made to bring (child's name) home. How did you make that decision?" "What types of decisions are you regularly faced with that cause you moral dilemmas, make you wonder about what is the right or wrong thing to do?"

Interviews lasted an average of 3 hours (family meeting plus individual interviews). The interviewers also kept notes on the child's condition, family interaction, and the home environment to complement the recorded interview data. These notes were transcribed into a word processor file within 24 hours after the interview.

Fieldwork observations consisted of observation intervals lasting ~2 hours, guarding against imposing additional strain on these already overextended families. These observations were scheduled during times that the family described as significant. This included situations that the family found particularly challenging as well as situations that were especially satisfying. Sample questions from the observation guide included, "How is space laid out in the home?" "Who is responsible for what?" "Who are the primary decision-makers?" "How is the 'medical' care of the ventilated child managed?" Detailed observations were recorded. The notes then were transcribed into a word processor file within 24 hours of the observation interval.

Thematic and Interpretive Analysis

The first level of data analysis, conducted by 1 of the co-investigators, consisted of a thematic analysis of all of the interview and observational data. The principal investigator then reviewed this analysis. Identified themes were arranged into meaningful categories, with close involvement of the entire investigator team. All data were analyzed in their original language, to preserve the participants' original meanings, although thematic headings were formulated in English only.

Summaries of interview and observation data outlin-

ing the significant themes described by individual families were produced and compared. A subsequent interpretive analysis was conducted, following the methods outlined by Zaner²⁵ and Benner.²⁶ This process identified the significant phenomena that characterized the moral experiences of these families, as well as factors that provoked or resolved them.

Methodologic Rigor

The methodologic rigor of this study was supported by the credibility, fittingness, auditability, confirmability, and saturation tests of rigor in qualitative research.^{27,28} The credibility, fittingness, and confirmability of this study were promoted through the interviewers' time spent with the participants, in "their world." This enabled the researchers to gain insight into the family's experience in its actual context. Throughout the course of data collection, the interviewers verified data analyses directly with participants. During interviews, paraphrasing and reflective listening were used to verify their understanding of the participant's report. As well, preliminary analyses and hypotheses of observational and interview data derived from each study participant were verified with previous participants and subsequent interviewees. Given the emotionally intense nature of the family experiences that were reported, the principal investigator held regular meetings with the interviewers (the research nurse and 1 of the co-investigators) to review how their reactions to these encounters might affect data collection. These measures supported the confirmability of the findings.

The investigators reported preliminary findings and analyses throughout the course of the study to several groups of health care professionals (HCPs) with expertise with this population. This involved small-group discussions as well as large-group presentations. Analyses were also reviewed with participants from the preliminary pilot study to seek their comments regarding the congruence of these findings with their own experiences, lending support to the credibility and fittingness of the findings. Data-collection and -analysis methods were reviewed by 2 of the investigators. This supported the auditability of this study. Data were collected until redundancies were observed in the concurrent data analyses. This helped determine the size of the participant group for the fieldwork observations. This supported the data saturation criterion.

RESULTS

Data analysis identified 6 principal themes: (1) confronting parental responsibility; (2) seeking normality; (3) conflicting social values; (4) living in isolation; (5) the voice of the child; and (6) questioning the moral order. An overarching phenomenon that best characterizes these families' overall experiences was identified: daily living with distress and enrichment. Each of these is

elaborated below. Brief excerpts of data are presented to help illustrate the meanings of these themes. Within each thematic category, subthemes are indicated by italicized headings. Although some themes were particularly important for some families rather than others in the group, study findings were not clearly related to any of the 4 diagnostic groups and 2 ventilatory modalities (tracheostomy and face mask). The findings reported below refer to the general experiences of all of the families in the study. For example, the themes raised by families whose children receive ventilation “invasively” via a tracheostomy were not systematically different or more distressed than for families of children with face masks.

Daily Living With Distress and Enrichment

The phenomenon that most adequately characterizes the overall findings of this study is daily living with distress and enrichment. The themes outlined below richly portray the distresses that these families face on a daily basis. Virtually every aspect of their lives was highly complicated and frequently overwhelming. An immediate interpretation of these findings is that families should be fully informed of the demands and hardships that would await them, encouraging parents perhaps to decide otherwise.

This would be but a partial reading of our findings, because despite the enormous difficulties described by these families, they also reported deep enrichments and rewarding experiences that they could not imagine living without. Life with a child who requires assisted ventilation at home involves living every day with a complex tension between the distresses and enrichments that arise out of this experience.

The conundrum inherent in this situation is that there are no simple means for reconciling this tension, yet this irreconcilability is particularly stressful for these families. Having their child permanently institutionalized or “disconnected” from ventilation (and life) would eliminate both the distresses and the enrichments. These options are outside the realm of what these families could live with, aside from the 1 family whose child is now permanently hospitalized, at a tremendous cost of guilt to the family.

Confronting Parental Responsibility

Parental responsibility was generally regarded as stressful, and particularly overwhelming early in the course of management at home. One mother said that the weight of the responsibility was so great that she could not do anything other than care for her child. She felt “stuck” at home because she had to be there all the time to meet her daughter’s needs. She also felt a great injustice toward the financial aspects of parental responsibility. It would cost her less personally to have left her child in

the hospital, because she would have been able to work, yet no reasonable funding was offered to help equilibrate this financial stress.

Parents directed remarkable energy and vigilance toward their children’s needs, extending themselves far beyond the home. One mother worked vigorously for 1 year to get her daughter into a school and subsequently did volunteer work at the school library to facilitate her daughter’s integration.

Some parents struggled with feelings of guilt about their inability to provide enough care and attention to their other children. They were especially distressed when these children overtly expressed resentment toward the preferential attention accorded to their siblings who require ventilation.

Most parents believed that they were not a priority for the medical system. For 1 family, the parents believed that their initial physician exhibited no interest in diagnosing their child’s condition because they believed that the physician did not value their child’s life, leaving the parents with a sense of exclusion, profound isolation, extraordinary responsibility, resentment, and distrust of the medical system.

Parents had to integrate the multiple, often contradictory, complex roles of caregiver, advocate, activist, educator, and case manager. This role complexity also extended into technical realms with frequent adjustments to the care to be provided. Parents were often faced with the challenge of complying with prescribed care while adapting its application to a more livable plan for the home context.

Parental Emotional Strain

The complexity and the magnitude of these children’s needs gave rise to extraordinary parental strains. These included significant physical and economic strains as well as particular forms of moral distress, such as having to balance 1 child’s fragility and life-sustaining needs with commonly competing everyday family needs. A remarkable and very ubiquitous form of moral distress that characterized these parental experiences related to their struggles to be “good” parents.

Is There Really a Free Choice?

Many parents described the strangeness that they experienced with regard to “making a decision,” as if there were really a choice when faced with life-support decisions. Most parents believed that when the alternative is to let your child die, “free choice” is really a virtual choice and not a true choice. Some parents said that they sometimes asked themselves whether they made the right decision, but this was commonly resolved by realizing that life without their child would be unthinkable.

Confronting Dependence

Physical Dependence

For 2 families, the parents were so overwhelmed with the physical work of caring for their growing, highly dependent sons that they chose to have them institutionalized. One parent noted, "As she gets older and heavier, it gets harder on us, so we have to explore other options and 1 or 2 options are either an elevator or a lift because we won't be able to do this."

Long-Term Dependence

One mother sought to have her adolescent daughter declared intellectually delayed so that she could be entitled to more government services when she grows older, such as supervised apartments. Knowing that her child would never be fully autonomous, this mother needed to ensure that she would not be solely responsible for her from age 18 onward. Indeed, several families expressed concerns about how their children's needs would be met as they grew older, when the parents would eventually become less physically capable of caring for them. This concern was accentuated for the families of children with neuromuscular disorders, who were more physically dependent. One family had already decided to create a trust fund to help the child pay for future services that the parents will one day no longer be able to provide. One parent was concerned that the schools for some of these children have lower standards, worrying that they will not acquire the necessary knowledge and skills needed to make them employable and financially autonomous.

Fostering Autonomy

One father spoke at length about his view that it is a father's responsibility to promote his child's autonomy. Although this could be demanding, this was also a tremendous source of enrichment for him, stating that he wishes every family could feel the love that he has been able to experience with his son.

Getting So Much in Return

Most parents reported that despite the difficulties, the struggle is worthwhile. Quoting 1 mother, "She's a sweet little girl, though. She's really worth it. So I think when you look past her disability, well, even with her disability, that she's a beautiful individual and couldn't even think of life without her. It is a bit more complicated, but it's worth every little bit of effort that you put into it because you receive so much back in return. It's really nice to have her in our life; without her, I think it would really be really, really sad."

Impact on Family Relationships

One mother spoke of the impact of having a child with a chronic illness on her relationship with her husband. When she was asked to give advice to another couple,

she replied, "It's your couple relationship that will really suffer. I mean, you argue because you're too tired. You argue because you're worried, because she's in hospital—things aren't going as you would like them to. You probably won't take it out on your neighbors; it's your spouse that will pay for it. 80% of people with a sick child end up separated; there's no other way to put it: it's hard for the couple."

Continuous Spectre of Death

Some parents spoke of the ever-present worry that their child might die at any time. There is a continual stress in knowing that there might be a ventilator disconnection and that the alarm might fail. Every morning, if things are particularly quiet, many parents immediately wonder whether their child is still alive. One set of parents spoke of the ever-present possibility that their child may die. The father said, "it's true that we always live with the idea that sometime we'll wake up and she'll be gone. We live with that. It's a stress."

Seeking Normality

Unfolding Concept of What "Normal" Is

All families sought to normalize their lives. They worked to establish common routines while redefining what was normal for their child who requires ventilation. The consequences of caring for these children had become a habitual, everyday experience for these families. One interviewer noted, "When one family was asked whether or not they received any help, the child wondered why this would be necessary. When we talked about school, he stated that going to a handicapped school would not be for him. Mother explained that he doesn't see himself as handicapped. Interestingly, the family did not mention until much later in the interview that the child requires complete physical care. Earlier in the interview, I asked what other kinds of care was required and the child looked at me strangely, seeming not to understand what I meant."

Striving for Stability

These families' normalization efforts seemed motivated by a fundamental striving for a stable family and home life. This "striving for stability" was sometimes undermined by limitations in family finances, family cohesion, and unpredictability of the child's condition.

In an attempt to identify related factors, families were grouped in terms of how much strain or instability seemed to characterize their everyday lives. On 1 end of the spectrum were families in which things seemed stable or "under control"; family life seemed relatively comfortable and calm. The home was relatively orderly, daily activities seemed comfortably "routinized," and the family was readily able to find time for the interview. Of 12 families, 8 fit within this category.

At the other end of the spectrum were families who seemed unstable or “on the verge of unraveling,” whereby every new incident that arose would significantly unbalance the family’s overall organization. Everyday life seemed chaotic. Making time for the interview was clearly very difficult. This was apparent for 3 families. One family did not fall clearly into either of these 2 groups, although it resembled the unstable group.

On examination of the features of the families who fell on these 2 ends of the “stability” spectrum, we noted that the stable families were stably employed and did not express any significant dissatisfaction with their financial circumstances, and their homes seemed materially comfortable, although no formal evaluation of socioeconomic status was performed. Although they expressed funding frustrations for adapted services for their child’s disabilities, they were able to draw on their own family finances to help manage the problem.

For the 3 unstable families, all were single-parent families. Two of these relied on social assistance for their revenue, and the third was able to return to work only by deciding on long-term hospitalization for her child. It was apparent that single parents who care for children who receive ventilation at home will necessarily be dependent on (very modest) state welfare payments, because the children’s care needs conflict with their ability to maintain employment. Financial status was the sole factor that clearly distinguished these 2 groups. Families with limited financial resources seem particularly vulnerable and disadvantaged.

Normalizing the Home

A common observation was that the homes looked “normal.” Medical devices and equipment were hidden or camouflaged so that they did not dominate the home environment. Ventilators, although beside the child’s bed, were covered with a cloth or towel, and oxygen concentrators were typically concealed under a table. Hospital-type beds were covered with colorful covers so that the special mattress or handles would not be readily visible. Ceiling rails for facilitating mobilization were visually discrete.

Wheelchairs that were needed for the more physically limited children required additional adaptations, including ramps for access or a customized dining table position. Of the 2 homes that had an elevator installed, 1 family had to pay \$10 000 from their own finances.

Not Wanting to be Different

Children who require ventilation did not want to be different from other children. One parental couple noted that the child did not want to participate in certain activities that require an overnight stay because she was embarrassed. The mother stated, “She doesn’t want to be different from others. She wants to be like the others.

The fact that she has a machine overnight doesn’t bother her because no one sees it. She goes to school and she is like the others. There’s no problem. She can do anything she wants. At nighttime, if she has friends over and they ask ‘what’s that?’ she’ll say ‘it’s my machine, I need it to sleep.’ But to be in a group at nighttime, she has never wanted to do that.”

Conflicting Social Values

Most families were hurt by discovering that their community attributed less value to the worth of the lives of their children with disabilities than they did. In addition to the difficulties involved in obtaining community services such as school or child care, which were more available to “well children,” these families were offended by the reactions that they encountered in their everyday lives. They were strangers in their own communities to the extent that both children and their families frequently felt obliged to seclude themselves within their homes.

Devaluation of the Life of the Child With Disabilities

Every family, in one way or another, was confronted with the reactions of friends and extended family, community members, and HCPs who questioned the worthiness of sustaining their child’s life. Some families faced HCPs who repeatedly wanted to revisit their decision to maintain ventilation each time their child was hospitalized with secondary problems.

One mother described that she has never regretted agreeing first to keep her infant and then to have her ventilated, yet, “I was criticized, I was told ‘this is senseless, if you didn’t have this child, you’d be able to do so much more with your life.’ ”

A significant amount of this felt devaluation was related to the actions of HCPs. One couple described how the fact that their child had trisomy 21 was announced. The physician said that their newborn was a “Mongol.” The mother said, “This is how they announced it—as rudely as that.”

One mother said, “We had a doctor at ... and he—I guess some doctors are hardened—and he said, he referred to K as a marginal child. And to me I thought that was really low. She’s a human being first and a human being with a disability second.

Another mother felt pressure from HCPs to let her child die: “After I had meetings with them, I had decided OK that’s it, the next time he has a blue spell I’m going to let him go. Because it was almost like a pressure. I felt a pressure. I felt very pressured to let him go when he was having blue spells.”

Some parents worried about the quality of staff who were assigned to their child: “Whenever my daughter has to go to the hospital, I’ll stay with her if they let me, because I can’t be sure that the staff that will be there will be competent, I can’t be sure that they’ll take the

time to review her chart. It shouldn't be like this. Right now, I'm fearful whenever they offer me services, because they're always poisoning services."

Social Responsibility and Resource Allocation

Although few data explicitly referred to resource allocation and social responsibility toward this population, these were clearly prevalent issues for these families. One mother pointed out some injustices in the system: "I had the choice when she was born to not take her, but I mean, we are parents, she was our child and we loved her. We took her. We don't have any regrets having had done it. She will be 19 on the 6th of July, and I will still have 119 dollars a month. It's nonsense. If we decided not to take care of our child, I'm under the impression that it would have cost the government a lot more than what they give us every month.

Another mother had to leave her previous job because they did not recognize her situation. This meant a significant decrease in salary, highlighting the way resource allocation policies can directly affect lived experience. One set of parents described how a malfunction of the wheelchair affects the lives of their sons: "They're very, very upset when their chair breaks. They're stuck in manual and they can't move and they're dependent on us and their whole life is in turmoil because they don't have their electric chair. Sometimes they go 2 weeks without their chairs. They get very depressed, they can't move."

Several families described how it could take years to get various devices, such as wheelchair ramps, to help adapt their home for their children with disabilities. They felt as though the child and the family consequently were trapped in their home, wasting years of their precious lives: "Another thing is that the house isn't adapted for my infant. Now we made our request to the Quebec Society for the Handicapped or something, I don't know. Except there's a list and it won't be this year. Now I'm stuck in the house with the infant. If I want to go on the grass, I don't have a ramp."

Living in Isolation

A common recurring theme exhibited by these families was a profound sense of isolation. On occasion, the profound loneliness that was expressed by some families was upsetting for the research nurse to witness.

Some parents were troubled by not knowing any other family who deals with the same problems. This was compounded by the fact that many of these children had rare disorders. The uncertainty of the future was described by some as unbearable. One mother stated, "I need to have people tell me what will happen, because I feel like I'm alone in the world."

Several parents explained that it took them several years to learn where to go for help. Finding appropriate

help required an extraordinary number of calls, numerous repetitions of their situation, along with frequent rebuttals of "we do not take care of that here," all because the child did not fit neatly into an established category. These repeated rebuttals further aggravated the parents' sense of segregation and isolation along with the feeling of wasting large amounts of precious time and energy in these futile pursuits of information or help.

Given the complex medical needs of their child, these families generally found that neither their extended families nor the medical system could provide any respite. They felt trapped, as arranging for baby-sitting was virtually impossible.

Families described several specific forms of isolation. For 1 family, it felt as though no one understood what they were living. Their extended family disapprovingly saw their situation as "crazy." Another family was told by members of their extended family that they should have their child institutionalized.

One family felt isolated by seeing their friends' children grow up, while their son with developmental delay did not: the universe moves on while the family feels stuck and left behind. Another family thought that although their neighborhood seemed quite nice on the surface, it felt as though the community did not accept their daughter with disabilities.

For 1 family with 2 highly dependent sons, the parents and the children preferred to enclose themselves in their home, to avoid the "stares" that they would get whenever they would go out: "I find that a lot of people are especially ignorant when you bring them to the mall. They're very ignorant. It's hard to deal with these people because you see their faces. They stop. They stare. They don't get out of the way. Their mouths are hanging open, and they are looking at them. And they get upset. What are you looking at? And it makes us angry. What are you looking at? Leave them alone. Move away."

In short, these families struggled to experience a sense of kinship. This longing for kinship was almost exclusively expressed by mothers. Only 1 father said that he would have liked to know another family who is living a similar experience. This suggests that there may exist an inherent gender difference in how this isolation is dealt with, or this gender difference may be coincidentally related to the fact that most fathers had lives outside their homes (ie, their work lives) that helped them overcome their sense of isolation.

What About the Voice of the Child (Patient and Siblings)?

In contrast to our previous findings,²⁹ the children in this study, both patients and siblings, were generally silent when asked to talk about their experience, except for a few notable exceptions.

Silenced Voices?

One mother stated that her sons seemed to have secret interior lives that leave even their parents wondering what is going on inside: "He wants to be around people, but when he's around them he won't talk.... I think one of the biggest problems for them is loneliness. It's a big problem. My nephews can't be here every day to be with them. So they want companionship. They want somebody to be with them, and we can't always find someone here every day."

Referring to the younger son, who was watching what was happening to his older brother, the mother reported, "That's what makes it hard for him, because he's watching everything that is happening to his brother that eventually is going to happen to him. So he's always quiet, always watching. You know there's stuff going on in his head, but he won't talk about it. I don't worry so much about the older boy. I worry about him being younger and watching. It must be scary for him.... I think one of the biggest mistakes we made from the beginning with this whole thing was that we did all the talking for them. We made all the decisions for them. We didn't really give them much choice in anything. And just later, in the last couple of years now we started realizing they're not infants anymore. Because in my mind they're still little boys. They're adults now, and it's time to start letting them make the decision. And I told them, from now on it's your body, you decide what you want to do. If you don't want something to happen to you, you have the right to say no. And A does it often. He says, 'No I don't want to,' or, 'I'm going to.' The little guy and he's very tiny he looks like ~8 or 9 years old. He doesn't look like he is going to be 18. I tend to forget that he's grown up, so we don't allow him a lot of decisions."

Child Worried About Being a Burden

Some children expressed concerns about whether they were a burden for their parents and family. One mother reported, "She asked me if I would prefer that she be dead, rather than have to drag this machine around. Just like that. 'I like it better that you're alive,' I said, 'we'll just have to drag the machine.' She's asked me this 2 to 3 times."

Ventilation as a Good Thing

Several children referred to their ventilators as good things, things that helped them breathe and feel better. One 13-year-old girl looked toward her tracheostomy and ventilator as a cure, without which she would otherwise be dead. She viewed her technologic dependence positively because it saved her life.

Sibling Concerns/Resentment

Some parents voiced concerns about the impact of the situation on the sibling, particularly their limitations in terms of activities. Indeed, the interviewers observed

several instances in which the siblings exhibited resentment toward the attention that their afflicted sibling was receiving. One mother reported, "I have to say also that we have 2 children, and K requires a lot of attention because of her disability, so we need to do a lot of things for her, and so sometimes it affects N. Sometimes she says we love K more than we love her and things like that. And it is really difficult to explain to a child, no we don't love her more than you, we love you both the same. It's just difficult because your sister needs more help."

Another mother said, "Whenever he's sick, my daughter has to learn to come second. Because of sickness, hospital things, my daughter has had to often miss things.... I try to make her understand that it's not because we love her less or that she has less space. It's just that she is in a different space and that she needs to learn to live with that. This does not always suit her, but she understands."

One sibling resented how having a brother with disabilities had affected her life. This seemed related to the afflicted child's inability to interact verbally with others. The sibling hinted at the possibility that the child chose not to speak: "Sometimes it's a little weird because it's not like you're talking to someone who can respond with something you'll understand pretty well. Because when you talk to him, if he's in the mood for talking, he'll only say a couple of words. So it's not like you're talking to someone who speaks fluently back."

One patient's sister exhibited resentment toward the imbalance of parental attention. She told her parents that they loved her less because she was not disabled. One patient (in late adolescence) said that he did feel guilty about the extra attention he received but believed that there was no choice. He would not be able to manage without the help. He did not see the "preferential treatment" that he got as a form of favoritism.

Questioning the Moral Order

Most families described their reflections about the moral order within their lives; that is, how are "good things" and "bad things" determined in the world. The predominant parental expressions in this domain conveyed a tone of "fatalism." Parents stated that this is a situation that no parent would choose for their child or family; it is very unfair, but there is nothing that you can do about it. It is thrust on you, and you just have to deal with it. For parents who hold more religious beliefs, they would refer to this as the path that God has chosen for them. Therefore you have to do it. This is what He has chosen.

"I think there isn't a human being on earth who is going to accept that their child is handicapped. You learn how to live with that. Quite simply. And I'm not the kind of person to feel guilty and my ex-husband neither. So I know that it isn't my fault that my daughter is like this. It is nature that wanted it this way. But you don't

accept it. You live with it and try to organize yourself the best you can and with the best of your knowledge. And to give her the best you can with the tools that you have, unfortunately.”

DISCUSSION

This study has uncovered the complex, largely invisible, lives of families with children who require assisted ventilation at home. Our findings demonstrate that these families face tremendous distress and enrichment on a daily basis. Much of the distress reported by these families is related to their encounters with health and social services systems. Although adapting to the child’s disabilities would already seem like an extraordinary challenge for most families, they also have to draw on their limited personal and material resources to negotiate highly fragmented and commonly unsupportive health and social services networks. This was particularly problematic for parents who felt the primary responsibility for ensuring that their children would receive the complex services that they required. These parents found themselves continually having to learn and manage new roles, most of which parents felt unprepared to assume. This is consistent with United Kingdom data on families with technology-dependent children at home.⁸

Although these parents seemed courageous to the investigators, parents resisted such characterizations. They typically believed that they had no choice, that they were doing what they had to do. The extraordinary complexity of these parents’ responsibilities corresponds with the wide range of invisible activities associated with parenting chronically ill children.³⁰ McKeever and Miller³¹ demonstrated that mothers of children with disabilities face particularly difficult obligations in striving to maintain the personhood and values of their children.

Despite the remarkable challenges, the children in this study seemed content with their lives. This serves as a credit to the extraordinary efforts of the parents, who continually worked to “normalize” their children’s lives. Indeed, this study identified a wide range of physical and psychosocial measures orchestrated by each family, aiming to create as “normal” a life as possible for their children (including the well siblings). In general, the families successfully overcame the barriers to normalization commonly faced by families with chronically ill children.^{32,33} However, Dyck et al³⁴ demonstrated that the adaptation required by these families involves a complex process of negotiation and restructuring to ensure that the home retains its personal and cultural significance.

The moral experience of these families implied a significant social dimension. These families faced communities wherein they felt confronted with “ignorance” and profoundly deprecating views toward disability. As they discovered the paucity of services available to them, they believed that their children with disabilities did not mat-

ter to their society. This was further reinforced by encounters with HCPs who questioned their wishes to continue ventilating their children, insinuating that their children’s lives were optional. This corresponds with the findings of Garwick et al³⁵ in their study of parents with chronically ill preadolescents.

These families lived highly isolated lives. This isolation was largely attributable to external barriers in most aspects of their community but was also internally chosen as a way of protecting the child and the family from hurtful social encounters. Ray³⁰ reported a similar finding.

This study highlighted that the decisional frameworks that commonly are used for this population are problematic. Treatment decisions for children draw on the best interests standard whereby the legal guardian (ordinarily the parent) is required to judge which treatment option will offer the greatest benefit in proportion to burden. Although this accepted legal and ethical standard has significant merits, it is exclusively patient centered for important reasons in that it helps protect the interests of vulnerable patients. However, this standard does not help families and clinicians sort out other (sometimes competing) interests. How are the interests of the well siblings, parents, and the entire family to be reconciled with the interests of the individual patient? Such decisions are usually made through a collaborative process with physicians and other HCPs. Similar to the study of Bach et al,³⁶ this study demonstrated that many HCPs hold negative prejudgments toward life with disability. Furthermore, HCPs are required to make such judgments in the context of limited time and material resources. How can families therefore rest assured that the medical opinions that they are receiving are as morally neutral as they would hope for?

These concerns are noteworthy in light of a study of initiation of home ventilation in children with neuromuscular disorders in which it was found that this decision was typically made in haste, with only 21% of families opting for ventilation.³⁷ Gibson³⁸ reported that physicians who care for patients who have Duchenne muscular dystrophy and require ventilation provided information in a manner that either discouraged or encouraged particular choices.

An additional question emerged with regard to the decisional process: what significance ought to be attributed to the voice of the child? Overall, patients as well as siblings were highly silent agents in terms of decision-making. This silence is noteworthy given the complex moral awareness of which children are generally capable.³⁹ Also, many patients had been receiving ventilation for only a small portion of their lives, such that they were aware of what life was like before ventilation. Did this silence mean that (1) these children were genuinely content and had no particular malaise to talk about, (2) they were socialized into the family’s “official policy” that everyone in the family was to think positively and

do their best to make things work, (3) these decisional matters exceeded the children's mental capacities, or (4) these children's experiences were beyond the realm of verbal articulacy—that they did not have words to express their unique experience?

With some of the adolescent patients, parents thought that they should protect their children from being involved directly with decision-making. It was remarkable that we had difficulty getting direct private access to many children, as most parents (but not all) preferred for child interviews to be conducted with the entire family. We consider this a fortuitous fault of our family design, which situated power primarily with parents, who in turn demonstrated how they managed access to their children.

This study has helped demonstrate the importance of establishing communication links among acute care centers, specialized clinics, and community clinics that provide home care for this population. Families can enable a significant normalization of their children's lives; however, this involves a highly demanding process that needs to draw on a wide variety of resources. HCPs at all levels along the continuum of care must coordinate their efforts in facilitating the transition from acute care to home care. This study emphasized the need to sensitize HCPs in acute care centers to the needs of this population once they return home. It was remarkable that most families were left on their own to procure community resources and that the most financially challenged families were the most limited in their abilities to manage everyday stresses. The Quebec Program for Home Ventilatory Assistance is the sole program that presently exists for this population. This program coordinates services between acute care and the community that are providing support to the family and the community clinics that are responsible for home care follow-up, but they, too, are faced with the same challenges of negotiating on both sides of the spectrum with HCPs and physicians who are frequently resistant to offer home mechanical ventilation.

Given the moral experiences of these families, it is important to support the development of services that can diminish the hardships that these families encounter and facilitate their potential for deriving as much enrichment as possible from their challenging lives. Some services do not imply major costs. Families found services highly fragmented, wherein they had to discover through trial and error which services were accessible and which were not. It would be helpful for these families to have information that explains how to obtain various services (eg, adapted transportation, subsidized home modifications, school services) within a sole family information booklet. We are currently adapting our own informational resources to address more adequately the needs revealed in this study. In addition, putting families in contact with other willing families can provide unique emotional support as well as valuable advice on how to find additional supports. However, prudence is required

in selecting such families, because the interests and the viewpoints of different families may conflict profoundly and create significant stress.

Our findings highlight the need to develop significant instrumental supports for these families. Although families personally ensure that their children are cared for, this comes at a major price to the family. Given that these families help limit health care costs to the state and insurance companies, it seems reasonable to consider that the long-term sustainability of such home-care programs should require significant family supports in the way of salary support, provision of part-time assistance within the home, and the development of suitable respite services.

The constancy of the care demands that these families face could benefit from innovative respite services. Facilities that are designed along the lines of a "camp model," where children would welcome the social opportunities that it would provide, could enable parents and siblings to have some time to tend to other activities without feeling guilty about abandoning their ventilated child. Such respite services should be available 12 months a year.

Finally, this study has demonstrated that families who have chosen to keep their children alive believed that they had no other choice. This study reports how they are living with their "choices." A limitation of this study is that we do not have the perspective of parents who chose otherwise: parents who decided to limit mechanical ventilation and consequently allowed their children to die. Additional research should examine the moral experience of these families in terms of how those parents came to feel able to make such choices and how they are living in the aftermath. Additional research is also required to investigate the experiences of families whose children have been weaned successfully from ventilation and had their tracheostomies decannulated.

Another limitation of this study is that its findings relate to a restricted geographic and health care setting. Other settings will likely have either more or less community supports in place, giving rise to potentially different experiences.

This study makes several important contributions. First, it has shed rich insight into the moral experiences of this group of families. Second, although this was a study of assisted ventilation, we believe that our findings can speak to the larger context of technology-dependent children who require home care. This is a link that needs to be examined more explicitly in subsequent research.

Third, although this study examines home care experiences, many of the findings relate to neonatal, critical care, and other hospital services. These settings need to examine their approaches to this population and rethink approaches that may impose preventable burdens on the lives of these children and their families.

Finally, this study is particularly innovative because it has examined an ethical and moral problem with an

empirical method. Such problems are typically investigated through conceptual analyses, without directly examining lived experience. These findings advance our thinking about how we ought to care for these children, through a better understanding of what it is like to care for them—and the corresponding major distresses and rewarding enrichments.

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