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Extremes, uncertainty, and responsibility across boundaries: Facets and challenges of the experience of transition to complex, pediatric home care

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Abstract

The availability of complex, pediatric home care (CPHC) allows ventilator-dependent children to live at home not hospital. The process of transition from hospital to home encompasses the morphing of responsibilities from uniquely hospital based to CPHC based. This study promoted contextualized understanding of transition using in-depth case-study methodology. A total of 26 adults were interviewed for their roles and responsibilities in transition; they represented members of the family, hospital team, home team, and government programs. Interview analyses revealed four major facets of transition, each accompanied by a significant challenge. Transition (a) was a continuous shift in responsibility challenged by precarious human resources, (b) was peppered with losses producing uncertainty and grief, (c) was focused on crossing jurisdictions in the face of polarization around knowledge, and (d) was heavily reliant on mothers leading to expectations of maternal extraordinariness. The overarching conceptualization emerged that transition entailed extremes and uncertainty in the bridging of boundaries.

Keywords

Canada, home care, pediatrics, responsibility, transition, mothers, caregivers

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Introduction

How does a change in place—hospital to home—shape responsibilities? There is a new population of ventilator-dependent children whose very life depends on the continuous use of medical technology. Until recently, if they survived the first few months of life, they would have called hospital home. These children have complex health needs (CHNs), ''ongoing healthcare needs related to the use of medical technology and who require the support of a range of professionals and agencies'' (Kirk, 2008: S64).

Availability of complex, pediatric home care (CPHC), along with advances in technology; restructuring of the health-care system; and public preferences allow children with CHNs to move from living in hospital to living at home (Peter et al., 2007). Home care now includes traditionally hospital-based therapies, yet the characteristics, resources, and responsibilities of home care starkly differ from those of hospital care. Lantos and Kohrman (1992) recognized uncertainty around which norms should prevail.

We focused on the process of transition from hospital to home to examine how the traditional norms of hospital and home morph into the unique responsibilities of CPHC. Using an in-depth case study, we examined the transition of two young, ventilator-dependent children. We aimed for contextualized understanding of the experience of transition by examining the perceptions of 26 involved adults.

Background

The disability rate among children below 5 years of age in Canada was about 1.6% in 2001, and approximately 63% of these children have chronic health conditions that are life threatening and introduce CHNs (Government of Canada, 2007). These numbers parallel other Western, industrialized countries. This population is expected to grow in number, in their needs and in their demands for care (Peter et al., 2007; Wang and Barnard, 2004). As CPHC is used more and more, ''radically new forms of childhood, parenthood and family life have been created, but are poorly understood'' (Carnevale et al., 2008: 5).

Many features of hospital follow these children home: medical needs, equipment, standards, and personnel. Living at home has been linked to many positive emotional, social, and physical benefits for the child with CHNs (Wang and Barnard, 2004). However, a constant tether to caregivers and technology profoundly impacts the child, his or her sense of self, and his or her actual and perceived capabilities (Arras and Dubler, 1995).

Parents of these children face the unpredictable and unrecognizable, as traditional childcare requirements are compounded and complicated by medical imperatives. The bulk of caregiving in CPHC is provided by parents but more so by mothers alone (Levine, 2005; McKeever and Miller, 2004; Peter et al., 2007; Wang and Barnard, 2004). Mothers, as caregivers, must perform complex medical tasks, supervise staff and patients, make decisions, solve problems, provide emotional support, coordinate care, handle equipment, and provide direct care (Carnevale et al., 2006, 2008; Given et al., 2008; Kirk, 1998; Kirk et al., 2005). CPHC transforms families: the meaning and structure of home changes, as do the daily activities of home life (Angus et al., 2005; Mah et al., 2008; Moore et al., 2010; Yantzi et al., 2006; Yantzi and Rosenberg, 2008). Social isolation and stigma have been linked to CPHC (Carnevale, 2007; Carnevale et al., 2006; Wang and Barnard, 2004; Yantzi et al., 2006). Nevertheless, Carnevale et al. (2006) noted that some of these families' daily lives contained gratifying experiences, which they could not do without.

Health-care professionals face profound changes to the content, nature, and location of their work in CPHC compared to the standardized and visible hospital setting (Arras and Dubler, 1995; Lewis and Noyes, 2007a). Professionals must share traditional and nontraditional responsibilities with mothers and paid nonprofessionals (Arras and Dubler, 1995). Homes have limited human and supply resources. With less direct supervision, CPHC can be freeing and disconcerting (Parks, 2003; Peter et al., 2007).

The majority of literature on children with CHNs separates the experience at home from in hospital. Two studies examined the link between these settings by exploring the process of discharge (Lewis and Noyes, 2007b) and the experience of negotiating transition (Kirk, 2001). Lewis and Noyes (2007b) provided practical guidance to navigate the complexity of discharge planning, based on consultations with professionals and parents. Kirk (2001) interviewed parents and professionals to find common agreement that parents lacked choice in assuming caregiving responsibilities from professionals, which fueled conflict not partnership (Kirk, 2001). This stemmed from little to no actual negotiation of roles, a high level of obligation, and few community-based alternatives to parents (Kirk, 2001). In this paper, we build on this literature to explore the hospital-to-home transition, beyond negotiation and discharge planning, using adult perspectives on responsibility in this complex process.

This case study was based in Alberta, Canada. Although services for young, ventilator-dependent children vary across jurisdictions, we recognized that many facets transcend communities by commonality or necessity. In Alberta, a public health sector program provides specifically for CPHC involving life-threatening airway management needs (Pediatric Advisory Team, 2009). Eligible families receive assistance in planning and preparing for CPHC as well as public subsidization of respite caregiving and some medical supplies while at home. Public social programs provide complementary supports to the health-related services, including nonmedical respite, funding for supplies or extraordinary medications, transport costs to hospital, and sibling care costs during hospital visits.

Methods

Research question

We used the hospital-to-home transition process to augment understanding of the responsibilities associated with CPHC. The research question was ''What do the parties involved in the care of young, ventilator-dependent children perceive as the process of altering and re-distributing responsibilities, obligations and costs for care upon the transition from hospital to home care?''

Case-study methodology

We used case-study methodology to frame the study, explain the research aims, and justify the methods. Case-study research ''emphasizes detailed contextual analysis of a limited number of events or conditions and their relationships'' (Dooley, 2002: 335). This research hinges on selecting an exclusive individual—whether person, program, or process—to analyze and explore for in-depth understanding (Stake, 1995; Yin, 2009). The case is a single, specific, bounded phenomenon; its boundaries are either easily distinguishable or explicitly demarcated (Luck et al., 2006). Flyvbjerg (2006) confirmed the value of case-study research: Contextual, in-depth knowledge can yield valuable and memorable understanding to counter predetermined ideas; expertise is closer through

case study than abstract rules; and the thoughtful selection of cases represents critical, not random, outcomes.

Our phenomenon of interest was the *process* of transition from hospital into CPHC for young, ventilator-dependent children in Alberta. We examined two specific cases of transition. The boundaries of the cases were not easy to define, but factors such as population, place, and technology helped with demarcation. The intricacy of transition made the case-study approach ideal.

Data collection and analysis. The primary research data were interviews of adults involved in the transitions. These cases involved specific children who were not interviewed. Purposive, then theoretical, sampling directed recruitment. We identified children who met the inclusion criteria and then used a snowball method to detect potential adult interviewees.

The inclusion criteria for the case children were as follows: (a) aged below 5 years, (b) had one family member who speaks English; (c) dependent on mechanical ventilation, (d) resident in Alberta, and (e) receiving some provincially funded home-care services. Eligible children were identified by one coauthor (I.M.). Clinic staff then contacted parents to gain consent for recruitment by briefly describing the research project in person or over the phone. One coauthor (K.P.M.) phoned interested parents to discuss informed consent for study participation.

Consenting parents were interviewed; they permitted the examination of their child's health records for study purposes; they identified professionals, individuals, and organizations involved in transition (who were then approached to participate in interviews); and they agreed to consider future focus group participation for feedback on preliminary findings. We sought a wide range of participants to represent the family, hospital team, home-care team, and government programs. We directed sampling toward roles and professions most prominent or representative during transition. One coauthor (K.P.M.) recruited professionals using their professional emails; a one-page research summary was provided in the email and follow-up phone calls entailed in-depth discussion for informed consent.

In-person, or over-the-phone, semistructured interviews were digitally recorded and transcribed. They ranged from 30 to 90 min. The initial interviews and questions inquired into the participant's experience with the care of that particular child. Questions targeted perceptions of others' involvement, roles, and responsibilities in the transition process as well as their views on what transition entailed. Interviews became more structured and direct as the research progressed to fill conceptual gaps and to approach theoretical saturation. Qualitative and thematic analysis directed the examination of the interview transcripts (Stake, 1995). For theoretical sampling, data collection and analysis were simultaneous to ensure the developing theory informed recruitment. One coauthor (K.P.M.) conducted the analysis, which was then critiqued and discussed with the other coauthor (I.M.).

Research ethics. The interview risks related to confidentiality were minimized by secure storage, limited access, and secure destruction of documents (Corbin and Morse, 2003). The risk of emotional distress was lessened by giving interview participants significant control (Corbin and Morse, 2003). All participants provided informed consent prior to participation, so participant competence, disclosure, understanding, and voluntariness were present (Beauchamp and Childress, 2001). This research was approved by the two major Albertan University Research Ethics Boards.

Trustworthiness. We pursued several well-established techniques to ensure methodological rigor, including careful scrutiny of findings and methodological strategies, corroboration of evidence,

and ensuring sufficiency of evidentiary scope (Forbes et al., 1999). We used an audit trail to follow research memo development and use, collection and reduction of data, and use of decision points. Ideas were discussed and compared between the research authors for credibility.

Different issues were compared and contrasted by interviewing participants with different roles in transition. Different perspectives on the same process helped clarify the major concerns, which promoted relevance of findings. Dissemination of research-in-progress at conferences invited feedback to further assess relevance. The final output was disseminated to the local clinical home care groups for feedback.

Findings

A total of 26 participants were interviewed (15 in person and 11 through telephone interviews) with the consent of two mothers whose daughters met the inclusion criteria. Three people did not respond to recruitment attempts. The participants included 3 family members (including the mothers themselves), 11 hospital team members, 8 home-care team members, and 4 government program representatives. The fields represented included nursing, case management, medicine, social work, respiratory therapy, and program administration. Both case transitions were staggered: Children were moved from an urban, specialist hospital to a small-city regional hospital to a rural home. This exaggerated the distance between hospital and home, which was conducive to our critical case study.

The overarching conceptualization emerging from this analysis was that the transition process entailed extremes and uncertainty in the bridging of boundaries. Four major themes and issues contributed to this conceptualization. Data analysis exposed four major facets of transition, each accompanied by a significant challenge:

1. Transition entailed *continuous* responsibility shifts, which were challenged by a pervasive lack of caregivers and thus precarity of support.
2. Transition was filled with *loss*, which challenged families and professionals with concomitant grief and uncertainty.
3. Transition involved recognizing and *crossing jurisdictions*, which polarization challenged.
4. Transition focused on shifting *considerable responsibility to mothers*, which challenged mothers with demands and expectations of extraordinariness.

We elaborate these facets of, and challenges to, the experience of transition from hospital to home. To support this interpretation, we provide short exemplar quotes from the transcripts. Sources are identified by the team they represent (family, hospital, home care, or government).

Continuous responsibility shifts and precarious support

The superficial goals of transition were to move the ventilator-dependent child home and to equip the family and local professionals for CPHC. As one hospital staff stated, "Transfer is the movement of the patient and we often think of the movement of the patient as the transition, but that's the transfer." (Hospital Staff No. 10). Another aim transcended these in the transcripts' language and content: the purposive shifting of responsibility to facilitate the thriving of the ventilator-dependent child (and her family) at home. "[In] the transition basically you're helping a family transition a child to home and preparing them for adult life" (Hospital Staff No. 10).

Accountability and liability for aspects of care of these children and families shifted along transition. This process generally began at the discussions around inserting a tracheostomy, which family, rural health-care professionals, and government programs were alerted about later. Shifts were neither simultaneous nor permanent. The dynamic context of transition confirmed this with changes befalling the child, family, professionals, and health-care system. The process was continual: The goal of shifting responsibilities directed actions in hospital, in moving home, and in being home. One home-care staff described this as

> *I think it's an ongoing process . . . I definitely think there was a beginning and I think there was . . . a process put in place. But I don't think that . . . you'd ever sign it off and say now we're done.* (Home-Care Staff No. 4)

The language of scarcity permeated many transcripts. Finding, securing, training, and maintaining appropriate paid caregivers to provide respite at home was a universally espoused challenge. "Over 2 years, [myself and] one RN [are] still there [with the family]. Everybody else has kind of turned over . . . We've probably gone through almost a dozen LPNs" (Home-Care Staff No. 5). Many people were involved in transition to CPHC, including professionals, parents, siblings, and community supports. However, respite caregivers were integral to allowing the child to be home. Home-care, hospital, and government personnel found human resources scarcer than financial ones, and the conditions of home care may have contributed to that

> *I mean a few of them left because . . . [they] found a full-time job and couldn't get full-time with [home-care] . . . [Another quit because she] couldn't handle the nights . . . I just trained another one but she did the training and never came back. I can't say I was surprised.* (Home-Care Staff No. 5)

Scarcity led to rationing and increased stress, costs, and responsibilities for mothers and hospitals. One governmental participant framed it as

> *It wasn't that we couldn't provide them with the hours either. It was people. We just had nobody and so then we had to determine a way within our program to prioritize and ration services . . . But we would prioritize the kids based on needs and of course choose the family that could go without a shift.* (Government Representative No. 1)

Delays in transition were attributed to this challenge. Given the extensive, continuous nature of transition and the unpredictability and precarity of respite, caregivers represented a significant challenge as the purposive shifts in responsibility were thwarted. This particularly impacted families:

> *The biggest delay always . . . is finding trained caregivers . . . [We] just can't find them . . . Some of them might work for a little while and then quit and then you're back to square one . . . Once these families get home . . . if they have a caregiver quit, it could be crippling to them.* (Government Representative No. 3)

Loss and uncertainty

Health professionals expressed and family members intimated that loss was ubiquitous along transition. Changes along transition meant certain things were lost, compared to the family's

pretransition experience and relative to other non-CPHC families. Bereavement of the losses left a convergence of grief, confusion, and trepidation in their wake.

Many instances of loss resulted from uncertainty accompanying new or unusual situations and unpredictable futures. One family member described it as

> *It was mostly just "time will tell" . . . that's not something somebody can answer for you . . . They can't say well this is what . . . you should do if she gets sick, . . . you have to play by ear.* (Family Member No. 1)

A hospital professional connected stress to this uncertainty: "No matter what you're taught, that first time where your child's trach gets plugged and you have to deal with that and . . . I can imagine your heart rate's 200. It's incredibly stressful whenever that happens" (Hospital Staff No. 9).

The unpredictability and "abnormality" of uncertainty was disconcerting for many. For example,

> *Dad was very emotional when we started talking about . . . transitioning home . . . In two conferences all he did is cry. He couldn't talk . . . He was very overwhelmed I think with just the knowledge that (A) she was disabled and (B) she would be coming home and there wasn't something that could fix this quickly.* (Home-Care Staff No. 7)

Uncertainty most prominently obscured the child's health and future expectations. The gravity of ventilator-dependent needs and the continuous nature of transition into CPHC put the child's—and family's—future into question.

Connections were lost along transition, which promoted other experiences of uncertainty and grief. Relationships changed; bonds were severed. Trepidation and uncertainty surrounded the novel relationships between family, professionals, and the home. For example, moving home meant both hospital professionals and mothers lost their previous connections forged during the child's hospitalization.

> *I think families tend to hang on to what they know and . . . they learn they can trust somebody so they tend to go there. And I think it's hard too: the hospital kind [of] cuts them off and then [urban home-care] cut[s] them off.* (Home-Care Staff No. 1)

New bonds had to be forged between mothers and the home-care team, which was not always easy or possible. Hospital professionals felt loss as well:

> *[When] a child [is] ready to go out the door and go home, I think there's a feeling of relief and happiness for the family, concern for what we know the family is going to go through and trying to prepare them for that . . . And then there's always a mixture of that with sadness because sometimes you've developed a nice relationship with a family.* (Hospital Staff No. 5)

Physical changes to home altered family connections to their living space. As a hospital team member questioned, "How do you make your house look normal, when you've [got] equipment all over the place and supplies?" (Hospital Staff No. 2)

Crossing jurisdictions and polarization of knowledge

Jurisdictional divides became quite apparent along the transition process. Some divides were crossed. Some jurisdictions became connected or coextensive. Other jurisdictions were further

polarized, which impacted the transition and its goal to purposively shift responsibilities. Ultimately, the appropriateness of boundaries was exposed and questioned.

The move from hospital to home revealed the connections between these two previously distinct jurisdictions. Mother, child, equipment, and expectations all traversed from hospital to home. Familial caregivers, mostly mothers, used the training and techniques typically within professional purview. Along the transition process, the features of hospital and home intermingled. Preparation was essential during hospitalization, which replicated home through education, rooming-in, or day passes. Once home, many features and connections to hospital remained such as equipment, personnel, or hospitalizations. This physical move was a watershed for the transition process, but the context before and after the move had much in common.

Other boundaries presented challenges to transition. Polarization along jurisdictional lines created hurdles to communication, collaboration, and conduct of responsibilities. Distinction particularly colored perceptions of knowledge and advocacy. Parties were confused about whose expertise to recognize. Conflicts and discords arose among the parties. Particularly prominent boundaries included urban–rural, medical–family, and professional–personal tensions. We elaborate only the last tension fully in this paper.

Professional relationships were distinguished from and promoted over personal ones by most professionals and government programs. However, mothers and those professionals with whom they had a close, and potentially personal, bond found personal relations paramount. A mother described this invaluable relationship:

> *On our first trip home, we came home with an NICU nurse. She's become a good friend. She's also the bereavement councilor in town so we had met her with the loss of my first son . . . [She] was key cause we involved her in so much cause she just knew [our child]. . . . She's the best advocate we could ever have.* (Family Member No. 3)

This promoted division not collaboration. One hospital professional found the professional team disconnected, with negative consequences:

> *All the caregivers weren't together. And because of that, the family could pick and chose who they had a connection with and the connection primarily was who was gonna give the family what they wanted, . . . a child who was healthy . . . So they would look for someone who would encourage them that their child is healthy or would be healthy.* (Hospital Staff No. 10)

The skills, advocacy, and priorities of professionals devalued those of mothers and the professionals closely bonded to them:

> *It was very difficult because the NICU staff had really bonded with this little girl and were advocating exceedingly strongly for the family . . . What they're asking for may or may not be able to be provided in the community . . . It got to be a bit bizarre because one of the nurses, who again worked NICU [and] who is a very strong advocate for families and clients, she became very, very involved on a personal level as well. So I had some hesitation because of . . . the blurring of professional boundary . . . My hesitation was just that how could anyone meet the expectations that the family had been given by this individual.* (Home-Care Staff No. 7)

Responsibilities became localized rather than broadly shared with parties turning away from each other.

Mother's responsibility and expectations of extraordinariness

The final aspect of transition was the considerable breadth and depth of responsibility falling to mothers upon transition into CPHC. At home, these mothers had extensive caregiving obligations as well as significant oversight and backup responsibilities. The extent and location of the fathers' employment and their rare provision of caregiving confirmed that familial CPHC responsibilities were in fact maternal. This confirmed previous literature findings (McKeever and Miller, 2004; Peter et al., 2007; Wang and Barnard, 2004).

While the ventilator-dependent child was hospitalized, mothers and hospital shared responsibilities in deciding, organizing, and providing care. The hospital realized its responsibility through different professionals. At home, sharing responsibility was less feasible. Fewer people, fewer resources, and isolated locale meant mothers had the bulk of responsibilities. One home-care professional described this as ownership:

> *[O]wnership falls onto the family. So yes they get support, but ultimately it falls to them . . . [W]e tell families that they're gonna have support, . . . that they get "x" amount of hours overnight. But you know what? If that person doesn't show, it doesn't affect any of us right? It affects the family.* (Home-Care Staff No. 2)

Rural and urban professionals in home care and hospital, as well as in government programs, had supportive but circumscribed responsibilities. A governmental participant noted these differences:

> *[T]he biggest change [between hospital and home] is going from 24 hours 7 day a week supervision in care; having emergency facilities and drugs and supplies and everything right at hand to going home and you don't have that. You have . . . what you have . . . [Y]ou might feel secure in your home because it's your own, but you still don't have the medical back-up and access to those resources at a moment's notice.* (Government Staff No. 2)

However, the challenges of polarized jurisdictions, precarious support, and significant uncertainty interfered with the availability and execution of support. This compounded the level of maternal responsibility.

Mothers were attributed with extraordinariness given the range of burdensome responsibilities they completed as well as their approach to such completion. Each mother was distinguished as unique and exceptional in her actions and reactions along transition into CPHC.

> *I think that had this mom not been on top of her game and the kind of personality and person that she was . . . this could have gone so drastically . . . completely different . . . But, you had a well-organized mom. You had a very dedicated [mother with] an attitude that she was a good advocate . . . [She] also worked with a cooperative spirit.* (Government Staff No. 4)

Reactions to obstacles were particularly telling:

> *Mom is exceedingly driven . . . [She's] a very strong advocate. She is a very forward-thinking person. She was always very positive and no roadblock was too big for her. She automatically thought past that in "how can we . . . move forward?"* (Home-Care Staff No. 7)

Occasionally, extraordinariness was negatively viewed as aggressive. For example, one hospital participant described it as follows:

> *Because [this mom] is different . . . that doesn't meet the norm in the Clinic . . . you deal with her and communicate a little different than [others] . . . [She] can be very demanding of the system and ourselves.* (Hospital Staff No. 2)

As a whole, the transition process appeared to expect and demand extraordinariness of these mothers to continually fill gaps and overcome challenges.

Extremes and uncertainty in bridging boundaries

Ultimately, this case study provides more depth to the hospital-to-CPHC transition process for young, ventilator-dependent children. This process entails extremes and uncertainty. The continuous nature of transition presents a never-ending, burdensome process: an extreme process that demands much of all but especially mothers. Maternal extraordinariness—whether extant through serendipity or demand—represents a prototypical extreme, not mean, along transition. Neither the myriad losses along transition nor their impact can be fully predicted. The precarity of support presents further uncertainty for families about the availability of caregiving support and about their own responsibilities.

These extremes and uncertainty populated a process designed to traverse a major boundary: the border between hospital care and home life. In crossing that boundary, other jurisdictions and borders became evident such as the professional–personal divide. The transition process was poised to bridge many boundaries, although in this case study only the hospital–home divide was truly connected.

Discussion

This research promoted an understanding of the character of a complex, impactful process in the lives of vulnerable children, families, health professionals, and the public health and social care system. The transition for young, ventilator-dependent children extended before and beyond the physical transfer of the child home. Elaboration of the facets and challenges of the transition experience illuminated its reality and impacts, especially for the adults involved. This will advance the informed consent process of parents contemplating CPHC for their ventilator-dependent children.

Professionals will be informed of the challenges faced by some families and colleagues. The supports required along transition became elucidated. For example, a major support for mothers once home would be for others to complete all their responsibilities to then avoid any need to "fill in" the gaps. The finding that mothers were linked to extraordinariness is commendable but disconcerting. Maternal extraordinariness in transition requires further research and consideration. Doing one's best is very different from being unlike anyone. If the transition mandates extraordinariness not excellence from mothers, then concerns arise for the sustainability of these girls' CPHC. For professionals and programs involved with these case families, this establishes an unappealing precedent of extraordinariness for future mothers of ventilator-dependent children.

The major challenges along transition into CPHC require further attention for redress or mitigation. Otherwise, delays and burdens will overwhelm the process. We propose potential mitigation strategies, which require further research on utility and appropriateness.

Loss due to uncertainty and changed relationships cannot be avoided, but professionals should recognize and address the signs, symptoms, and implications of bereavement. If recognized and addressed, the negative ripple effects of loss, such as interference with responsibilities, could be avoided. The availability (and acceptance) of counseling for family and staff would promote emotional health and productivity.

The lack of human resources has been connected to a systemic, social devaluation of care (McKeever and Miller, 2004; Peter et al., 2007; Yantzi et al., 2006). This pervasive devaluation requires broad, sustained promotion. Only then will people want to fill these roles. Potential approaches include lessening home care's isolation through daily interactions between evening caregivers and the home-care team (e.g. a central evening representative to call and discuss issues), establishing stability similar to institutional positions (e.g. unionization, benefits, and full-time opportunities), and advertising campaigns to alert everyone—not simply the nursing community—of the value of caregiving work.

The jurisdictional divides promoted polarity that pushed (or pulled) the parties away from each other. Promoting trust could mitigate this polarization. For example, families and those close to them seemed to distrust the medical team to provide all that was necessary and feasible within the public budget. Meanwhile, the medical team appeared to distrust the family to do all that was within their capabilities. With each side distrusting the other, suspicion overwhelmed cooperation. Increased transparency, greater dialogue, recognized vulnerability, and more of the all-to-difficult faith could promote trust (Brien, 1998).

This case study aimed for in-depth, contextualized understanding. We cannot comment on the prevalence of these experiences among other transitions into CPHC. While the research aimed to excavate perspectives equally from the family, hospital, home-care, and government teams involved in transition, most participants represented hospital and home-care professionals, 19 professionals compared to 3 family members and 4 government representatives. The research may have benefited from greater family and government representation. Mothers were often the sole family representative to the health-care system, so the dearth of paternal and other familial participants was consistent with practice realities (Arockiasamy et al., 2008; McKeever and Miller, 2004).

The openness of the recruitment process, including the recognized case children, may have introduced a recruitment bias against those wishing for absolute anonymity. The feedback on this analysis was provided mainly through conferences and meetings with bioethics and home-care professionals. We could not convene a focus group with family and home-care participants due to participant unavailability or disinterest. One home-care participant provided emailed feedback that indicated her perspective was captured. This inability to convene a focus group may affect one aspect of the findings' rigor. Nevertheless, other aspects of trustworthiness were completed (e.g. fit and grounding in data) and confirmed analytical appropriateness.

Different professionals and programs were involved in the process of transitioning young, ventilator-dependent children from hospital to home. These professionals affected and were affected by this process. Each challenge involved professionals. Their understanding of the facets and challenges to transition will promote better and smoother journeys for these children and their families. Given her prevalence and predominance along transition, mothers appeared critical for success. However, the breadth and intensity of her responsibilities demands recognition, support, and reevaluation. Transition is not simply about moving a child home. It also entails shifting a global and unremitting responsibility to a mother, while framing support through local and distal professionals and programs.

While this research promoted greater understanding about the process of transitioning young, ventilator-dependent children from hospital to CPHC, it raised concerns that should be addressed. The validity and implications of maternal extraordinariness, as well as the potential approaches to mitigate the challenges of transition, require thoughtful care and attention.

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