Taking the call-bell home: a qualitative evaluation of Tele-HomeCare for children

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Abstract

Tele-HomeCare (THC) delivers health care at home using telephone technologies. A THC service was developed as an adjunct to existing hospital and community care systems. It connected healthcare providers to children and families at home, during the initial transition from hospital to home, using video-conferencing phones and remote vital signs monitors. The goal was to support the transition from hospital to home, for children with subacute healthcare needs. This paper reports the qualitative evaluation of THC and describes the experiences of families supported by THC. A total of 16 mothers, four fathers and two adolescents from 16 families participated in a series of interviews conducted before, during and after THC. The interviews focused on the impact of THC on the children, on the families, and on their overall healthcare experience. Analysis of their accounts identified three subthemes: the stable child, a sense of security, and the healthcare-proficient parent. These subthemes were consistent across all time points and participants. Together they contributed to the overall effect of THC: the timely *reunification of the family* at home. THC was consistently reported to be an important resource that supported children and families during the transition from hospital to home. The benefits to children and families observed in this study may have also been a consequence of returning to their home environment, since THC allowed these children to be discharged home at a much earlier period. However, our findings are consistent with previous reports of the benefits of THC. Thus, THC is a successful method of healthcare service delivery that enables a safe return home with professional support provided remotely.

Keywords: child health, complex care needs, family-centred service, health services delivery, qualitative methods, telecare

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Introduction

Restructuring has placed increasing pressure on hospitals to discharge patients as early as possible. These changes have raised questions as to how care should be delivered to individuals who do not meet the current criteria for hospitalisation yet have care needs that are too complex for community care services. Innovative healthcare service models have been developed to address this issue. One such model is Tele-HomeCare (THC), which uses

emerging technologies to deliver enhanced health care at home for adults with chronic health conditions (Sparks *et al*. 1993, Johnston *et al*. 1997, 2000, Chumbler *et al*. 2005).

There have been a variety of published reports on various forms of THC since the practice began in the mid 1990s. Most are descriptions of clinical experiences that focus on adults with specific clinical conditions and provide evidence of the benefits of THC (Lenane 1994, Friedman *et al*. 1997, Kaye 1997, Rooney *et al*. 1997, Der Shah *et al*. 1998, Short & Saindon 1998, Warner 1998, Whitten *et al*. 1998, Dansky *et al*. 1999, Puskin 1999, Demiris *et al*. 2000, Finkelstein *et al*. 2000, Johnston *et al*. 2000, Shaul 2000, Tang & Venables 2000,Bowles & Dansky 2002, Downey 2002, Dansky & Bowles 2002, Hailey *et al*. 2002, Scott 2002, Celler 2003). The strongest evidence comes from a randomised control trial (RCT) that found patient satisfaction, quality of care, access to care and cost of care to be similar for community-dwelling adults with chronic diseases who received THC compared to those who received traditional home care (Johnston *et al*. 2000). These results are supported by qualitative results from other American studies of adults with chronic conditions (Dansky *et al*. 1999, Agrell *et al*. 2000, Finkelstein *et al*. 2000). Canadian research suggests that THC enhances access to health care, is associated with high patient and provider satisfaction, and appears to be cost-effective (Elford & Ramsay 2000, Health Canada 2000, Palmer *et al*. 2001, Scott 2002, Siden *et al*. 2002). An ongoing RCT in Alberta, Canada, is expected to support these previous findings (Hebert *et al*. 2004).

The best information on THC for children has been reported from Japan and Sweden. In Japan, videophones are used to support the care of children requiring home ventilation. Direct access from home to the paediatric intensive care unit eased families' workloads, reduced their anxiety and sense of isolation and improved the quality of life of the patient and family (Miyasaka *et al*. 1997). The Swedish SABH project (Hospital-Managed Advanced Care of Children in Their Homes) began in 1998, and provided advanced clinical care 24 hours per day to young children with a variety of health conditions (Bergius *et al*. 2001). Their programme of house calls and remote monitoring was found to be economically viable and provided high-quality clinical care at home. More recently the palliative care team, at the Royal Children's Hospital in Brisbane, Australia, has demonstrated that an Internet-based videophone using phone lines can be used to provide palliative care in the patient's home. They were initially faced with call quality difficulties (audio and video freezing) but were able to rectify this problem to provide a feasible service to their patients (Bensink *et al*. 2004).

Thus, the existing literature suggests that THC may be effective for adults with a variety of chronic health conditions and shows promise for use in children with subacute and complex healthcare needs. However, a detailed qualitative examination of families' experiences with THC has not yet been reported. Our a priori expectation was that THC would have an impact on the child, the family and the overall health experience. The objective of this study was to generate an in-depth understanding of the experiences of THC through the eyes of children and their families.

Methods

A cross-sectional qualitative descriptive study was initiated to explore children's and parents' experiences of THC. The research was approved by the Research Ethics Board at the Hospital for Sick Children (HSC). All primary caregivers were provided with written information describing the study and signed informed consent documents. In addition, children 5 years of age or older were asked to provide formal assent.

The THC service was developed at HSC in 1997 to smooth the transition from hospital to home, so that children with complex care needs might be cared for at home (Young *et al*. 1999, 2004). This service was implemented as an experimental intervention in 2000. This hospital provides tertiary care to a large metropolitan community. The THC service linked community-based home care and hospital-based services using vital signs monitors and two-way video-conferencing equipment connecting the home and hospital via existing telephone lines. Hospital-based monitoring centre nurses provided both scheduled and on-demand support 24 hours/day, 7 days a week, for a maximum of 6 weeks. Families also received regularly scheduled in-home visits from community-based home-care nurses which continued after the discharge of THC, if necessary. The monitoring centre nurses were the hub connecting hospital-based professionals to home-care professionals, and families. All families receiving THC lived within a 30-minute radius of HSC and had the ability to safely and quickly reach a community-based emergency department if necessary. In addition, the primary caregiver was required to have a functional knowledge of English. A schematic diagram of the service is provided in Figure 1 and details of the design have been previously published (Young *et al*. 2004).

Purposive sampling was used to select a heterogeneous sample of 16 families from a larger intervention trial, involving 63 families who received THC between June 2000 and September 2002 (Dick *et al*. 2004). Diversity was sought with respect to children's ages, sex, clinical condition, and prior hospitalisation experience.

Each family participated in three semi-structured interviews, sequenced to capture distinct aspects of the

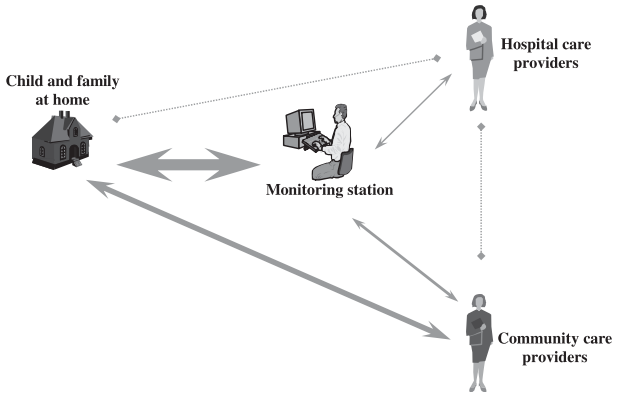

Figure 1 Schematic of Tele-HomeCare.

families' experiences throughout the THC trajectory. The interviews focused on three areas of investigation: the impact of THC on the child, on the family, and on the overall healthcare experience. More specifically, the interview guide included probes to inquire about their expectations regarding going home, the typical home life of the family, their thoughts and experiences regarding the THC equipment, and their relationships with healthcare providers. They were also asked to synthesise the overall benefits/drawbacks of the THC service from initial education to discharge. Interviews were conducted with children's primary caregivers, and with children 5 years of age or older who were willing to be interviewed. Children were interviewed separately from parents to ensure that the children's perceptions of THC were elicited.

The first interview (labelled as *Pre-THC* in the Results section) was scheduled to occur prior to the child's discharge from hospital, but after THC training had been completed. Two weeks after discharge from hospital, the researcher travelled to each family's home to conduct the second interview (labelled as *During THC*). The third and final interview (labelled as *Post-THC*) was conducted over the phone with the primary family caregiver 2 weeks after the THC equipment and service had been removed from the families' homes.

Each interview was audio-taped, transcribed verbatim and analysed using QSR*NUD*IST software (QSR International 2000). We began with an expectation that THC would have an impact on the child, the family and their overall health experience. The intent of the analysis was to explore families' THC experiences in greater detail and to identify the elements that contributed to these impacts. Accordingly we used a qualitative descriptive approach, as described by Sandelowski (2000), to capture outcomes that could not be measured by standardised quantitative outcome measures, and that could not be anticipated at the beginning of the study. An iterative approach was used and began as soon as the data were collected. New data were compared to emerging categories throughout the analysis. The intent was to develop a framework of how THC impacted families.

Results

Sixteen families were recruited from the larger THC intervention trial and a total of 48 semi-structured interviews (three per family) were completed. These involved 16 mothers, four fathers and two adolescents. All interviews were completed during a period of 13 months (October 2000–November 2001) and averaged approximately 1 hour in duration (range of 30–120 minutes). The sample was evenly distributed between high- and low-income families. All participants had functional knowledge of English; however, 44% of the parents did not speak English as a first language. Almost two-thirds of the parents had exposure to college or university education.

The children involved in care by THC included a comparable number of boys ($n = 9$) and girls ($n = 7$), most of whom were less than 1 year of age and eight had been hospitalised since birth. All children had potentially life-threatening health conditions and required continued clinical support and vital signs assessment several times each day. The diagnostic groups included encephalitis, respiratory insufficiency requiring mechanical ventilation, and complex congenital heart conditions. There were no adverse events attributed to participation in the THC study (see also Table 1). In addition to receiving THC, all children received traditional home-care. It is important to note, however, that most of these children would not have gone home with vital signs monitors were it not for the THC service. These children would have remained in hospital until such monitoring was required less than three times per day, and could be provided by visiting home-care nurses.

This series of interviews with a variety of family members from 16 families generated a rich description of the THC experience. The synthesis of data from the three areas of investigation enabled the identification of three subthemes: the stable child, a sense of security, and the healthcare-proficient parent. These subthemes were consistent across all time points and were expressed by all participants, but few linkages between the subthemes and the overall theme were explicitly articulated by the participants. These subthemes lead to the identification of one overall theme, timely reunification of the family, which was a product of the overall effect of THC (i.e. main theme). The three areas of investigation, the contributing elements, the subthemes and the overall theme are shown in Figure 2 and described in detail below.

Table 1 Sample Characteristics

Characteristic	Categories	Number	Proportion of total sample (%)
Clinical unit	Cardiac condition	5	31
	NICU	3	19
	General paediatrics	6	38
	Critical care unit	1	6
	Respiratory medicine	1	6
Additional medical technology support	Home IV	1	6
	Ventilatory support	4	25
	NG or G-tube feeds	11	69
Family structure	2-parent families	12*	75*
	Single-parent families	4	25
Siblings	0	8	50
	1	7	44
	2	0	0
	> 2	1	6
Employment status pre-hospitalisation	2 parents working full time	8†	50†
	2-parent family with 1 non-working parent	4	25
	Single parent working	2	12.5
	Single parent not working	2	12.5
Total sample		**16**	**100**

*One of the two-parent families was part of a large extended family living in the same dwelling.
†Of the eight families with two working parents, mothers were on maternity leave, two of whom planned not to return to work.

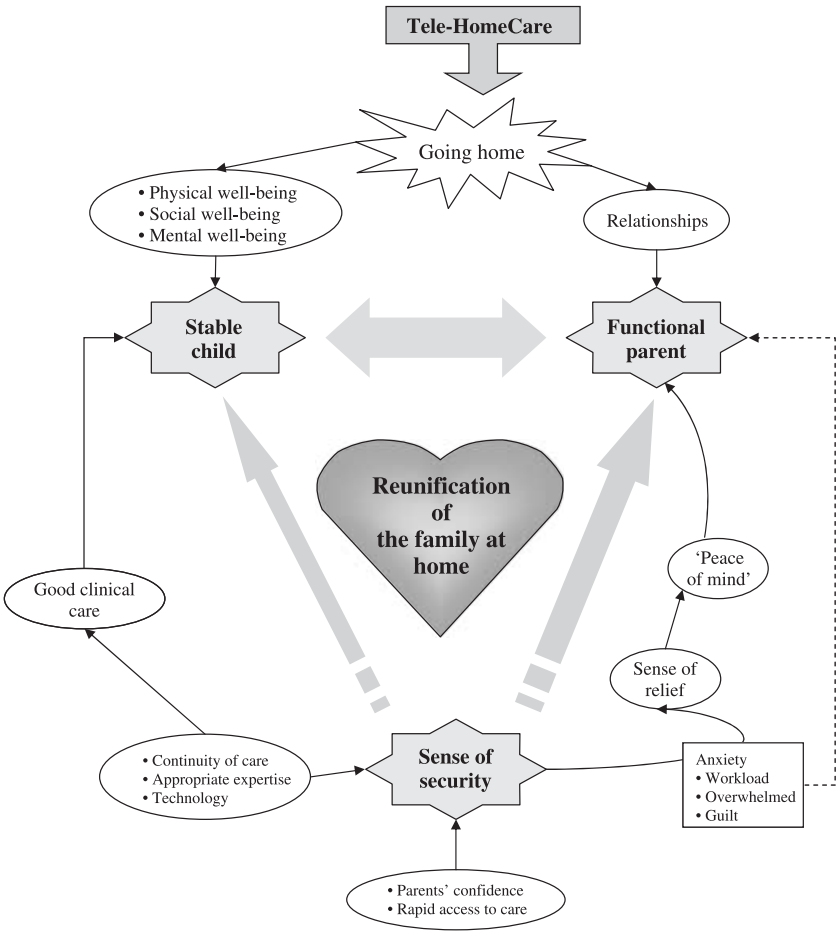

Figure 2 Impact of going home with Tele-HomeCare.

Impact of THC on the child

In their initial interview, all parents expected that THC would have a favourable impact on their children. These expectations were confirmed in the follow-up interviews, with participants reporting that THC had improved children's *physical*, *mental* and *social well-being*. The return home enhanced relationships with parents, friends and siblings, improved eating and sleeping and resulted in improved general health. However, this was not a direct causal relationship.

I really think being at home makes a huge difference just being at home and having your life back to normal. I think that is the best medicine. If you have a choice, like when there is a small amount of home nursing and being monitored by SickKids [THC], I think it's much better for the patient and the family. Just having a normal life, that's it in a nutshell. (parent 6, Post-THC)

Furthermore, parents stressed that the discharge to home would not have occurred within the same time-frame without THC.

I was a mess. If I hadn't had that equipment [THC] I don't know if I [we] could have gone home. I remember the nurse upstairs saying to me 'are you OK with this?' and I said 'yeah, I think I'm OK with this.' If I [we] had to go home just cold turkey, I don't know. (parent 4, Post-THC)

Once at home, parents and children confirmed that home was their preferred place despite concerns for the fragile health status of these children. Parents agreed to take on complex care at home because they believed that their children would benefit. One parent described the decision as follows:

Obviously when you're in the hospital, you're around everybody that's sick; I mean that's why you're there. So, like I said, it would have been tough for Cindy to stay down there [hospital]. I think this [THC] has sped up her recovery and even her eating. Obviously it's better eating at home, we can feed Cindy whenever, even if she doesn't eat when we're eating. Just that kind of stuff so I definitely think it [THC] is a plus if everything is stable with Cindy. (parent 4, During THC)

A further observation by adolescent patients was that THC did not interfere with social relationships but aided in the maintenance of friendships.

At the hospital you're sick and if you're at home it's all normal. Even though you're sick at home it's still normal.… They [friends] could come over and they see what the machines are doing. They actually think it's cool. All the equipment I show them … They think everything is cool. (adolescent 12, During THC)

These quotes are consistent with statements of all participants that show the impact of home on the recovering child, and link this critical event to the availability of THC.

Impact of THC on the family

Participants described the impact on family in terms of *parental emotions*, *relationships with others*, and *domestic workload*. The support offered by THC was particularly important for parents who had little experience caring for complex health conditions. Some were first-time parents of infants who had not been home since birth.

Parental emotions

THC elicited emotions that changed over time. Parents reported feeling *overwhelmed* with the thought of going home and this contributed to heightened *anxiety*. A mother (whose infant had been hospitalised since birth) was anxious about the impending hospital discharge resulting in contradictory statements. 'The care of Betty is not overwhelming. I basically know everything individually; it's just the thought of making sure I remember to do everything.'

The same mother reported later in the interview that: 'she [felt] like a registered nurse without a degree … quite panicked if you want to know the truth' (parent 10, Pre-THC).

Parents reported feeling a *sense of relief* once they had completed the THC training and knew that they could take their child home with THC support. When a father was asked what he was looking forward to after hospital discharge he stated:

Just to relax. It's hard to relax here [in the hospital]. You are scared when you are here. People are very sick here. People are sad because things are bad. Sometimes we can't sleep when we hear something [cardiac and respiratory arrest codes] happening. It makes us more scared. (parent 5, Pre-THC)

Parents also described relief from guilt related to domestic obligations.

We can give more attention to our other kids [now that we are going home with THC]. We can give more time to our other stuff at home. (parent 7 Pre-THC)

As the families settled into their homes their *sense of relief* increased.

If I don't want to dress I won't. I don't have to drive and be stressed out about getting to the hospital. Having privacy in the sense that you are not in a room with five people or someone constantly coming in to check Beverly or poke at her. So being at home makes it much easier and much more comfortable for us. (parent 13, During THC)

Another parent reported a feeling of *confidence in their ability* to provide care to their child:

It's been great to be able to come home with the equipment. We've been very comfortable with that. I'm feeling very confident. Now, I don't feel like I need to call everyday. (parent 6, During THC)

This suggests that access, rather than actual use of THC, was key to the sense of confidence families developed with THC.

For most families THC had been a stepping-stone to becoming independent with the care of their child. One parent recognised that: 'Tele-HomeCare helped us through a tough period' (parent 14, Post-THC), but they made no requests to extend the THC support at the termination of the study.

However, a few parents reported that anxiety had escalated upon the removal of THC.

I think that the equipment and the service should be a lifetime thing especially for parents with children who are often in the hospital. (parent 12, Post-THC)

Another mother who had extensive experience with her child's multiple admissions to hospital over many years, felt that discontinuing THC was a setback that raised the sense of risk: 'It's like you're back at the starting line, waiting for the gun to go off' (parent 12, Post-THC).

Relationships with others

THC also had an important impact on other family members. Typically, during hospitalisation, one parent stayed at the hospital with the sick child while the other cared for the children at home. THC was perceived as contributing to the rebuilding of the family unit by allowing the child and primary caregiver to return home and resume their typical family roles.

One of the adolescents expressed relief to have THC because she felt it decreased the burden that she placed on her mother.

I don't think it is fair for the parents to be the nurse [having to take vital signs, interpret them and make clinical decisions] and the parent. The Tele-HomeCare nurses are professionals. They know all of that. (adolescent 12, During THC)

Workload

Parents anticipated that they would experience an increase in their workload upon discharge home because they would assume both the general care of their child and the clinical nursing care provided in the hospital. Despite this, all parents embraced these responsibilities because they would be in their own home environment and they would be together as a family.

Going home will be a little bit tough but we will be happy because we will save time. We spend a lot of time travelling everyday … It will be hard to handle my child all the time at home, because now the nurses at the hospital take care of her medication and everything, but at home my wife will have to spend the whole day on her. (parent 7, Pre-THC)

Impact of THC on the healthcare experience

The families' healthcare experience, while receiving THC, was enhanced by the following factors: *rapid access to care*, *continuity of care* and *expertise*. Although we expected that the healthcare experience may be altered by a negative impact of technology on the home (Wong 1991, Arras 1995, Sudia-Robinson 1998, Murphy 2001, O'Brien 2001, Kirk & Glendinning 2004, Wang & Barnard 2004) this was rarely observed. However, because of its importance, one quote related to the impact of technology has been included.

Rapid access to care

Participating in THC created a feeling of having 'immediate' access to professional help.

It is just like being in the hospital and you just press the nurse call button. (adolescent 12, Post-THC)

Instead of having to wait and ponder, should I or shouldn't I, or is my child going to get worse or better, at least with THC I had somebody that could confirm or just say 'You know what, you're just being paranoid, settle down, calm down, you're just being a mother'. (parent 12, Post-THC)

Parents expressed satisfaction with their ability to contact a 'live person' rather than a 'voice mail service', and expressed that the rapid access to specialised health care was particularly important for children who have subacute, complex needs. Although many parents mentioned a 'constant link' to nurses and physicians, their actual pattern of linkage was intermittent (e.g. four times per day for 5 minutes per contact). As < 1% of THC contacts involved a physician, it was the perception of physician availability and not actual need that was of great importance to parents. A dependency did not occur as a result of THC.

Continuity of care

Families who had previous experience with the transition from hospital to home, expressed concern about the discontinuity between the hospital and community care system. What appeared to be most important to these families was the opportunity for THC to link them back to the hospital. These parents predicted that going home with THC would give them a sense of continuity because they were 'taking part of the hospital with them' (parent 15, Pre-THC).

The Tele-HomeCare nurses already know everything about Charlie. It's not like I'm calling into some kind of help line, that I have to re-educate them about Charlie. (parent 11, During THC)

They welcomed the opportunity for a more gradual transition. Parents felt that they would 'remain in the loop' and be able to discuss and follow up on issues because of the presence of THC. The service also enhanced the transference of care from hospital-based care providers to community-based professionals. Parents reported that there was a gradual shift in the roles and responsibilities and the majority felt prepared for the transition off of THC.

For some families there was an additional advantage of THC when their children required re-hospitalisation.

Cause when you walk out of SickKids Hospital … you think, 'I am walking out, how do I get back in here', like how do I get a phone call into somebody who knows Cindy and what she's been through as opposed to just walking into the Emergency and then starting fresh again. So it was just a total link to somebody who knew everything that Cindy had gone through. (parent 4, Post-THC)

These statements underscore the value parents placed on continuity of care. They did not expect to retain the same providers, but wanted the transitions between providers to be seamless and gradual.

Appropriate expertise

All participants agreed that THC provided a pathway for children to be at home yet still receive specialist care.

I know that I still have a link to SickKids and I can say 'well my child is doing this and I'm not really comfortable about it' and then THC gives me some input on my findings; and clearly they [HSC staff] know. (parent 11, During THC)

THC provided parents with timely access to 'expert care' at home and extended the scope of care beyond that possible with traditional home care, and was seen by families as an adjunct rather than an alternative to traditional home care.

Impact of technology

It was clear that the video component played an important role during the early stages at home, enabling parents to become confident in caring for their child and helped establish a strong rapport with their healthcare providers. Some concerns regarding the THC technology expressed by some participants related to the quality of the video picture (e.g. 'the picture makes you look like you are moving in slow motion' – parent 13, During THC) and the size of the equipment. Dissatisfaction with aspects of the technology occurred as the child's condition improved and parents' reliance on visual nursing assessments diminished. Most families (63%) elected to use audio-only communication with the monitoring centre by the third week at home. Hence, dissatisfaction with the video component often indicated that a family had outgrown the need for it, and allowed families to initiate the first step of a gradual transition off THC.

Synthesis of shared experiences into subthemes

The synthesis of the three areas of investigation lead to the identification of three subthemes: the stable children, a sense of security, and the healthcare-proficient parent.

Stable children

THC's *impact on the child* and the *impact on the healthcare experience* directly supported the clinical stability and improvement of the children while being cared for on THC. It is clear from parents' accounts that there were definite advantages for the physical, mental and social well-being of children.

I think Bobbie is going to be just fine. The home environment will be different for him. Bobbie will have less interruptions, less noise, less people poking at him. (parent 3, Pre-THC)

Because at home I'm used to everything. At home I know that I'm not as bad as I was at the hospital … I'm back to my normal life as possible. (adolescent 12, During THC)

THC linked the home and hospital environments electronically to bring the resources and expertise of the hospital into the home. In this way THC contributed to children's recovery and well-being.

A sense of security

THC's ability to improve access to expert care and continuity of care, combined to give parents a *sense of security* not only in the healthcare their child was receiving, but also in their own ability to care for their child.

Tele-HomeCare was viewed as a 'safety net' or a 'life line' providing the parents and the children with a sense of security: 'THC was something to fall back on. It was a big security blanket' (parent 10, Post-THC). Knowing that access to the hospital and expert care was only a phone call away provided 'peace of mind' to the parents (parent 14, During THC).

The parents and children articulated that it was the knowledge that they had access if needed rather than actual frequent use that was the essential ingredient in THC.

Because it [THC] is a service available to me, in the back of my mind 24 hours a day, which I have here, at SickKids 24 hours

a day. So whether or not I use it is another question. But knowing that it is there. (parent 10, Pre-THC)

I don't know. It [THC] is just good. It's a safe – it's a – it's like security. (adolescent 12, During THC)

Throughout all phases of the study, THC contributed to this *sense of security* by increasing parents' comfort and confidence levels and enabling them to provide appropriate care to their child. It did not make families dependent on THC, but rather it promoted the development of parents who were ready to take on the care of their children's complex healthcare needs.

The healthcare-proficient parent

Parents described a type of cognitive dissonance around the time of discharge from hospital: they so desperately wanted to return home with their child, yet did not want to leave the resource-intense hospital environment. One of THC's effects on parents was to enable them to become proficient healthcare providers to their children and thus feel secure at home.

Because we talk to the THC nurses very regularly, and that actually brings up our confidence … Slowly we are getting like a normal family and instead of relying on the healthcare system to take care of us; we are standing on our own feet here. (parent 14, During THC)

In addition, it indirectly promoted parents' mental health and well-being.

Successful transitions home appear to be intimately tied to the development of healthcare proficiency among parents. This occurred gradually because THC provided consistent access to expert care, which served as on-the-job training and support. The period following discharge from THC was a time of pride for most parents, because they were now independently caring for their child and had their privacy back. This effectively counterbalanced the negative impacts of increased workload, anxiety, and stressed relationships. There were no reports of feeling dependent or perceptions that homes have become medicalised.

Overall effect of THC on reunification of the family

THC was central in supporting the reunification of the family at home through a variety of mechanisms. The most prominent of these was increasing the families' *sense of security* that in turn diminished their *anxiety* and resulted in a sense of *relief*.

Upon arriving home, one mother found it difficult to find words to describe how she, her husband and child were feeling, 'There's really no words to describe being at home. We feel like we are in heaven' (parent 2, During THC). This view was also expressed by one of the adolescents: 'At home my family can stay and be at home with me … with THC it is great. It's like being at the hospital except I am at home' (adolescent 12, During THC).

In summary, this service contributed to the clinical stability of the child, and provided a sense of security that enabled parents to develop the skills necessary to care for their child at home. These elements were key in facilitating the reunification of the family at home.

Part of you wants to go home but part of you feels very comfortable with the security of the hospital but THC gave me the security to go home. (parent 4, During THC)

The tension all of the time is with being at the hospital, and not having any privacy. The two of us constantly wanting to be with our child. Coming home was so wonderful. The happiest moments were when the three of us were at home together. It is unbelievable. (parent 2, During THC)

Discussion

THC was an experimental service designed to support the clinical care of children with complex and high-intensity care needs during the initial transition from hospital to home. The service was developed to address the apparent discord between the best site in which to provide health care and the best psychosocial environment for the child.

The qualitative information gathered in this study has resulted in a rich description of the THC experience for families whose children were making the transition from hospital to home. This study found that THC facilitated the transition home and that the benefits of THC extended well beyond the children to enhance the well-being of parents. The study began with the a priori expectation that THC would have an impact on the child, the family and the overall health experience. Our findings are consistent with these expectations, and expand on them by adding details regarding the mechanisms through which the overall effects were achieved, as shown in the resulting framework (Figure 2). The main theme identified was reunification of the family at home. In addition, this study was able to identify the elements and subthemes that contributed to this effect. There was remarkable concordance of perceptions across a diverse group of participants.

The greatest asset of the service was the potential access it provided. Families needed to know that there was a group of familiar and knowledgeable healthcare workers available to them at all times, and that there was a way to get 'back in' to the acute care hospital. The benefits of access and the associated reduction in anxiety has previously been reported (Miyasaka *et al*. 1997). The importance of access and its essential role in generating

a sense of security was reported by Agrell *et al*. (2000) in a THC service for adults.

Families also identified the importance of video-conferencing as a mechanism for access in the initial phase at home to aid in the development of a rapport with the THC team, and as a medium for ongoing reinforcement of skills that were learned in hospital. The pattern of use of the video equipment proved to be a marker for the development of a sense of security. Technology dependency was not a factor. This finding has also been reported in adult populations (Dansky *et al*. 1999, Finkelstein *et al*. 2000).

Caring for a technology-dependent child at home poses several challenges for parents who are often expected to provide and perform all necessary medical procedures for their child as well as co-ordinate and advocate for services on behalf of their child while maintaining their parental role (Kirk & Glendinning 2004). In the THC study, the entry of medical technology and caregiver roles into the home was less intrusive and disruptive to family function than the prospect of ongoing hospitalisation, and provided additional security for these families. The overall findings of this study also offer an explanation for the strong preferences families reported for THC and their high levels of satisfaction with the service (mean satisfaction score of 82.8), previously reported by this group (Dick *et al*. 2004). Preliminary reports from a THC study of community-dwelling adults living with chronic health conditions also show a high degree of satisfaction among both patients and providers (Atack & Duff 2004).

In combination, these findings suggest that care at home during the subacute care phase can be as good as in hospital, that families prefer to be at home, and that THC facilitated the transition home. Recent publications regarding children requiring long-term ventilatory support confirm that home remains the optimal site of care for children with complex health issues (Hewitt-Taylor 2004). The main advantages of home include reintegrating these children back into their families and communities, thereby, maximising their developmental potential and their overall quality of life (Hammer 2000, Sasaki *et al*. 2001, Amin & Fitton 2003). These publications support the results presented here and suggest that the need for THC remains relevant.

Limitations

This was a qualitative descriptive study of a small sample of families from one metropolitan centre (Toronto) in Canada. Telehealth initiatives are generally designed to address issues of geographical barriers to care and limited human resource. This study was no different, in that urban traffic congestion proved a significant barrier to travel and the nursing shortage limited the availability of night nursing to those families who required it.

The sample included children with a variety of different clinical conditions and previous hospitalisation experiences, family compositions, and cultural backgrounds. All of these characteristics present challenges to this study. However, due to the serial nature of the interviews, and the consistency of positive findings and passion of the discourses, we believe that the findings are valid. Furthermore, the findings of this study are consistent with the results of quantitative evaluations of satisfaction with care, and of quality of life from this population, in which a rigorous pre-post statistical analysis was used (Dick *et al*. 2004, Young *et al*. in press). It is also important to recognise that there may have been a recruitment bias. The service was contingent on parents' willingness and interest in accepting the care of their child at home. A previous report from Sweden (Bergius *et al*. 2001) suggests that the value of home and being with family compensates for any additional burden of care. Thus, while purposive sampling ensured the representativeness of the clinical and familial diversity seen in the larger study, the results are not necessarily generalisable to all families. Furthermore, the results of this study predominantly reflect the perspective of parents.

Conclusions

THC extended hospital resources into families' homes to augment traditional home care for 6 weeks. It greatly enhanced the continuity of care, and was effective in making the transition from hospital to home more gradual. The initial 2- to 3-week period at home was a critical time for reinforcing learning done in hospital and modifying care plans to suit the home environment. During weeks 4–6 most families realised they needed less support, were developing strong ties with community care resources and were preparing for discharge from THC. THC accelerated the hospital discharge process and provided additional support benefits to those parents and community care providers. Thus, the primary benefit observed in this study was the timely reunification of the family at home.

THC and similar types of services must foster the integration of healthcare services, rather than being driven by technological possibilities. The service must be dynamic, and requires flexibility by the hospital staff, home-care providers and families. Although today's technology is easier to use, the THC issues that were prevalent in the late 1990s (licensing of physicians across jurisdictions, reimbursement for services and malpractice insurance) continue to be barriers to full acceptance of THC (Brown 2005). These issues need to be addressed if THC is to become part of mainstream health care.

THC needs to find its rightful place. Currently, THC appears to be best suited as an adjunct to traditional care helping fill the 'gaps' between hospital-care and traditional home-care by building a bridge to ease the transition home. It is an adjunctive tool that increases access and provides continuity of care. THC may offer benefits to other populations whose healthcare needs cannot be met by traditional community care resources. Such services can and must foster integration of healthcare services but must be adjusted to fit the unique healthcare needs and social situations of each family. The focus must be clinically driven and change in response to clinical needs, not be dictated by the technology alone.

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