



Acquisition of professional knowledge and parental knowledge within the PRIFAM intervention program

PELCHAT, D., & LEFEBVRE, H.

Abstract

Training of perinatal nurses in the PRIFAM family intervention program and implementation of the program led to a retrospective study on the knowledge acquired within the partnership relationship. The study sought to identify the theoretical, experiential and transformational knowledge acquired and the co-learning accomplished by the perinatal nurses and families of children with trisomy 21 who took part in the study. The results show that partnership, the relational basis for the PRIFAM program, promotes sharing of knowledge and the development of parental skills, and that the reciprocal, mutual engagement of each partner generates co-learning that promotes family adjustment and makes nursing practice more fulfilling.

Keywords: knowledge, partnership, disability, family, transformation

Background

The birth of a child is a natural, happy event. But for parents whose child is born with a disability, it becomes a nightmare. The ordeal has major implications for the future of the child and the whole family (Bouchard & Pelchat 1997; Bouchard, Pelchat, Boudreault & Gratton-Lalonde, 1994; Pelchat, 1989, 1994, 2006a; Pelchat & Lefebvre, 2005; Pelchat, Lefebvre & Bouchard, 2001). The family embarks upon a battle for survival that mobilizes all of its energy but also lets it discover its potential (Cyrułnick, 2001). The experience of a family whose child has a disability is forged from distress but carries the potential for hope, learning and growth (Cyrułnick, 2001; Pelchat & Lefebvre, 2001; Pelchat, Lefebvre & Damiani, 2002). The parents need support to help them work through the ordeal (Pelchat & Lefebvre 2005). Yet a variety of studies have shown that intervention with these parents is often insufficient, delayed and non-systemic, and that clinicians are poorly prepared to respond to these families' needs (Pelchat, Lefebvre, Proulx & Reidy, 2004). Professionals report not knowing what to say or do to help anguished families in this enormously stressful situation. Their training is usually based on the bio-medical model, covering solely the expertise of the professional (Pelchat & Berthiaume, 1996; Sandrine-Berthon, 2000). While this is an excellent model for acute illness situations, it proves inadequate for dealing with a disease that has become chronic or a permanent disability. To bridge this gap, Pelchat (1989) developed the interdisciplinary family intervention program known as PRIFAM. The PRIFAM training program is based on health education (Deccache & Meremans, 2000; Lacroix & Assal, 2003; Sandrine-Berthon,

2000), and recognizes that the effectiveness of the professional intervention is strongly linked with the degree of cooperation between the partners (Bouchard, 1999, Pelchat, 2001, 2006a; Pourtois, 1999; St-Arnaud, 1995; Tessier, 1996)

As a result of recent reforms in health services and social services, families are now more involved in managing their child's development and the services responding to their needs. Professionals recognize that families possess a body of indispensable knowledge accumulated in daily life and through contact with their social environment but do not know how to utilize this new knowledge. Moreover, professionals find it hard to forge a relationship of trust with the families. Yet knowledge can only be shared if there is a family/professional partnership that fosters cooperation.

When the PRIFAM program was applied as part of a longitudinal study, parents and nurses alike reported that they had acquired new knowledge (Pelchat, Bisson, Perreault, Ricard & Bouchard, 1998; Pelchat, 2001; Pelchat, Bisson, Ricard, Perreault, & Bouchard, 1999; Pelchat, Ricard & Lefebvre, 2001). Parents said the program helped them to develop their capacity to solve problems arising from the stressful situation and devise strategies for adapting to life with their child with a disability. The nurses found they acquired new professional and personal skills that enhanced their practice with families.

A retrospective study of learning was conducted, to identify the type of knowledge acquired by the parents and nurses within the partnership relationship during implementation of the PRIFAM program. The study focused on perinatal nurses trained in the PRIFAM program and parents with a child born with trisomy 21 who received the PRIFAM intervention.

This article describes the PRIFAM program and the related training, before presenting the results of the retrospective study.

PRIFAM program

This program was developed by Pelchat (1989), as part of a qualitative research project and was co-constructed with the collaboration of five couples with a child with a disability. Based on a philosophy of family care, the program's objectives are family autonomy, promoting internal and external family resources and putting them to use, and actuating competencies to help the family adjust to the situation and provide optimal care for the child (Pelchat, 1989; 2006a, 2006b; Pelchat & Lefebvre, 2005).

A number of elements make this program original: the fact that it begins as soon as the child is born; the fact that both parents are involved; the care taken to meet the needs of each member of the family; an approach reflecting the individual and family dynamic as well as the influential interplay with the environment; the importance attributed to the skills of each individual within a family/professional partnership that promotes family well-being and professional fulfillment; the use of reflective practice about and in action, viewing the family as an indispensable ally in the quest for solutions.

The program sees each parent in terms of their potential for action and helps them to move forward. PRIFAM objectives focus on five family subsystems: individual, conjugal, parental, familial and extrafamilial (Table I). Each of these subsystems interacts with the others and each in turn interacts with the system and affects the way it operates. The interplay between the interactions in each subsystem creates an impact and produces something new: a synergy that helps to give new meaning to the event.

Table 1
Specific Objectives of the PRIFAM Program

Subsystems	Specific Objectives
Individual	Foster in the father and mother a perception of the situation that helps them to work through their grieving for the child they expected. Ascertain each parent's perceptions and beliefs about the situation; challenge any that hamper adjustment and strengthen those that promote it.
Conjugal	Help spouses to understand each other, support each other and work through the process of grieving for the child they expected, allowing each to recognize their strengths and skills as a spouse.
Parental	Foster a trusting relationship between the parents and the child and encourage the development of attachment; support siblings and help them to adjust.
Familial	Foster exchanges within the family concerning the perception of the situation and acknowledge the role of each person in the adaptation process.
Extrafamilial	Help parents to maintain meaningful relations with the extended family, their circle and their working environment, and to use the assistance of community resources and health professionals as effectively as possible.

Because the PRIFAM program views families as key partners in the quest for solutions, the intervention is designed to set up an intersubjective dialogue between the nurse and the family. This dialogue enables the participants to acquire knowledge, thereby helping the family adjust to the transitional situation.

The following sections deal with theoretical foundations, the clinical model of the PRIFAM adaptation/transformation process and the relational bases.

Theoretical foundations and clinical model of PRIFAM adaptation/transformation process

The clinical model of the PRIFAM adaptation/transformation process (Figure 1) proposes an innovative insight into individual and family dynamics following the birth of a child with a disability, and the reciprocal influence of the problem on the family and the family on the problem (Pelchat, 1995). This model is based on a set of theories and approaches, including Lazarus's stress theory (Lazarus & Folkman, 1984) and Boss's model of the management of family stress (1993, 2003). The premise for this model is that the degree of stress experienced by each family member is determined by cognitive evaluation of the situation and by the strategies they possess. This cognitive process is itself influenced by internal, external and contextual factors and factors related to the disability. Internal factors are those that affect individual and family perception and relate mostly to the individual: knowledge of the problem prior to the birth, the individual's history, personality, age, sex, previous personal problems (addiction, mental health problems) and own future plans. External factors are ones associated with the family and extrafamilial subsystems: conjugal, parental and family dynamics prior to the child's birth: conjugal, parental and family plans for the future, and the attitude and support of the extended family. Contextual factors are of two kinds, those related to the family and those related to the intervention. Family-related contextual factors involve the type of family

(nuclear, one-parent, blended), its socio-economic characteristics and its cultural background. Intervention-related contextual factors are the characteristics of the intervention and the relationship with the health professionals. Factors related to the disability itself will also affect people's perception of the situation. Like Lazarus (Lazarus & Folkman, 1984) and Boss (1993, 2003), the adaptation/transformation model views adaptation to the situation as depending not on the severity of the problem but on how the parents perceive it. Factors relating to the disability, such as whether or not the sequellae are permanent and the uncertainty surrounding the problem (diagnosis, prognosis and treatment), will affect people's perceptions of the situation. These perceptions in turn influence their choice of strategies (individual, conjugal, parental and extrafamilial subsystems) that help or hinder them in the adaptive tasks leading to adaptation/transformation. According to the psychodynamic theory of crisis in a grief situation (Caplan, 1964; Lindemann, 1966), how a person works through the grieving process will depend on their individual dynamic and resources. The goal is to accomplish adaptive tasks, grieve for the child the parents had hoped for and support the adaptation/transformation process.

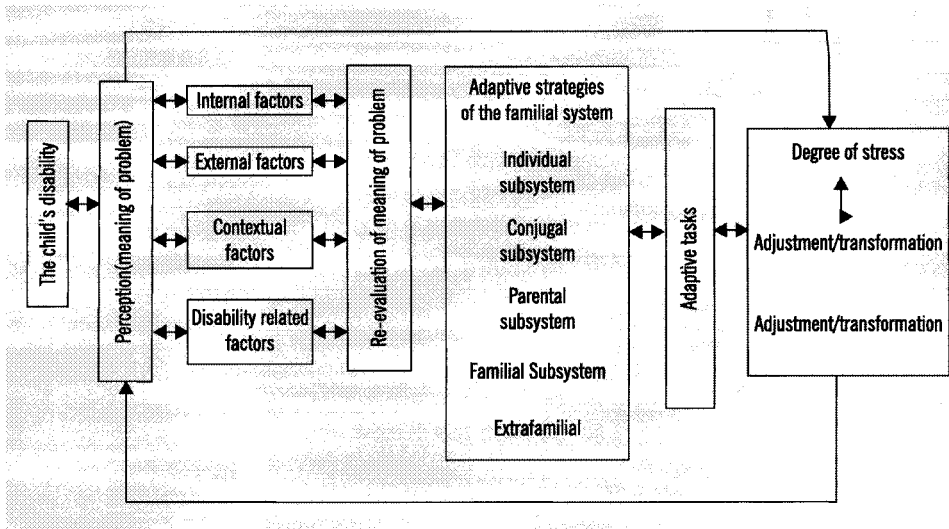


Figure 1
Clinical Model of the Adaptation/Transformation Process

Within the adaptation/transformation model, the systemic approach (von Bertalanffy, 1993) enables us to understand the reciprocal influences of the individual dynamic and family dynamic, while the ecological approach (Bronfenbrenner, 2000) throws light on environmental factors; these represent significant variables that may influence individual and family dynamics following the birth. The adaptation/transformation model (Pelchat, 1995; Pelchat & Lefebvre, 2004, 2005) provides insight into the adaptive strategies involved and the tasks parents have to accomplish in order to move through the process of adaptation/transformation leading to attachment to the actual child and maintaining of relations with significant individuals within the familial subsystems and the extrafamilial system.

Relational bases

Partnership is the relational model used in the PRIFAM between families and clinicians (Bouchard, 1999; St-Arnaud, 2001). Through recognition of their mutual resources, the reciprocal nature of their relationship and the pursuit of a common goal, partnership fosters the development of a relationship of trust between the partners, leading the family to mobilize its strengths and adjust to the new situation. It allows an equal relationship to be forged between the partners. The players share their perception of the situation and their resources; this in turn lets them *appropriate their own skills* and inspires confidence. (Bouchard, 1999).

All the authors agree that you have to be a partner in decision making in order to cooperate. But to become a partner, each person has to recognize their own competencies and those of the other person. *Self-determination* in taking charge of themselves is a matter of feeling able to assume responsibility for making decisions and clarifying their objectives and roles (Dunst, Trivette & Deal, 2001). This leads to *autonomy*, which concerns the person's will to act and decide for themselves to go from words to actions. Forging of the parent-professional partnership begins at the very first meeting. Once people get to know each other, they want to cooperate and share knowledge, skills and resources.

The partnership implies that the care team uses its expert knowledge to help the family modify a difficult situation, while at the same time acknowledging the family's special know-how and competence as regards finding solutions, applying them and evaluating them (Lucyshyn, Nixon, Glang & Cooley, 1996). For all this to happen, there has to be mutual exchange in an equal relationship between everyone involved. The professionals analyze the family's health situation through the prism of their disciplinary knowledge and professional and personal experience, which they share with the family. The family analyzes the health situation through the prism of its own knowledge and experience, which it checks against the expert knowledge of the professionals in order to better understand the impact of the health problem on the family. This complementary knowledge melds to form a common body of knowledge (Bouchard, 1999)

PRIFAM training

The PRIFAM training program is offered by the Faculty of Nursing at Université de Montréal (Québec, Canada) at the master's level, for nurses working in perinatal care. The training comprises a theory segment and a practical segment. The website at www.scinf.umontreal.ca/famille makes the training available to nurses in remote regions and throughout the French-speaking world. In addition to providing theoretical information, this website enables nurses and trainers to contact each other and promotes reciprocal learning.

The intervention is holistic, dealing with the whole person; it takes into account the relationship with the person and their family from an ontological perspective, with an awareness of the ethical, moral and spiritual dimensions involved. Accordingly, care extends beyond the medical situation, viewing emotions as factors that foster or hamper the person's progress. Transformation is regarded as individual evolution that is predictable and results from being steeped in the situation.

The *theory segment* comprises 125 hours of intensive training. It covers the theories behind PRIFAM, the principles of systemic family intervention with families in a stressful situation and the principles of family empowerment and family appropriation of competencies in caring for a child with a disability. In the *practical segment*, nurses implement the PRIFAM with

families, and their progress is tracked in group feedback meetings. Nurses are encouraged to reflect on their relationship with the families and their intervention with them, so that they gain more respect for the families and become more open-minded about what the families face.

Group meetings, held first weekly and then monthly, include feedback sessions for as long as the program operates, i.e. 6 months. These sessions encourage introspective thinking by the nurses and group reflection on their practice, values, attitudes, beliefs and prejudices concerning the family and the child's disability. The PRIFAM is based on the principles of reflective practice, which promotes a concerted effort for reflection and evaluation as regards clinical practice and education of the family. Reflective practice makes everyone start to think about what they know and build on this knowledge (Schön, 1994). Nurses become aware of their own knowledge, know-how and self-management skills, and those of the family, starting from elements that emerge from self-mediation, and mediation with the family and other partners. This type of practice extends to the families; intervention by the professionals using systemic questions and the sharing of hypotheses encourages families to think about their own experience and develop expert skills for coping with their situation. The reflection process becomes reflectivity when the process leads to changes in the nurse's practice (St-Arnaud, 2001).

The meetings generate reciprocal learning among the trainers, nurses and families. When the nurses' practice is analyzed with the families, they become guides to the nurses just as the nurse is a guide to them, because of the reciprocal relationship they forge together.

The PRIFAM training enables nurses to bond with families whose child has a disability and go through the experience with them. The nurse occupies a place within the experience, by the parents' side, instead of her traditional position as an onlooker external to the ordeal. The same nurse takes care of the family and also liaises with the various clinicians, institutions and organizations. Her presence ensures seamless follow-up after the doctors inform the parents about their child's disability.

PRIFAM intervention

The intervention involves six to eight meetings between the nurse and the family. The meetings can continue for as long as the families wish. The first one takes place at the hospital a few hours after the child's birth. The nurse is present when the physician breaks the news of the child's disability to the parents, or she meets the parents immediately afterwards. Subsequent meetings take place at the family home. The number of meetings depends on the needs of the parents.

During these encounters, the nurse explores the factors affecting the parents' perception of the situation; she reinforces facilitating beliefs, challenges restrictive ones, and encourages each parent to express their feelings and interact with the child.

The Intervention

The intervention consists of six to eight meetings between the nurse and the family.

- Two or three meetings are held at the hospital, the first a few hours after the child's birth and the rest as required by the parents. The nurse is present when the physician breaks the news of the child's disability to the parents, or meets with the parents immediately afterwards.

- Four to six meetings take place at the family home during the first six months of the child's life. The number of meetings depends on the parents' needs. At these meetings the nurse:
 - explores factors influencing the parent's perception of the situation;
 - reinforces beliefs that facilitate life with the child, for example, "my child has the means to develop";
 - challenges limiting beliefs such as "I must have done something bad for my child to have a disability";
 - encourages the parent to express their emotions and interact with the newborn. In so doing, the nurse:
 - adjusts to the parents' pace;
 - focuses on certain interventions, e.g. normalizing the parents' experience, recognizing the value of parents' adaptive skills, boosting their sense of competence, tapping into mutual support between spouses, making use of support from the extended family and utilizing the available resources.
- At these meetings, the nurse and the parents devise different ways of doing things in order to better organize the care required by the child. These are ideal opportunities for:
 - reflecting on the situation together and sharing each other's experience;
 - explicitly recognizing the value of parents' competencies;
 - normalizing the behaviour of the newborn and siblings;
 - determining (the parents') satisfaction levels as regards task sharing, decision making and each other's commitment to the family.
- After each meeting with the family, the nurses analyzes each subsystem, and the interventions and learning accomplished:
 - she takes the time to reflect how the family operates and her own role in the family dynamic;
 - she shares her thoughts and talks about her experience with the families, with the group of nurses and trainers.

The nurses works at the parents' pace, acknowledges their adaptive skills and cultivates their own feelings of competence; she encourages them to support each other, call upon the support of the extended family and use the resources available. These meetings with the nurse are an ideal opportunity for people to reflect on the situation together and share their respective experience, discover that their reactions are normal, and determine their satisfaction as regards task sharing, decision making and the involvement of each family member. After every meeting with the family, the nurse analyzes each of the subsystems and interventions and the learning accomplished. She takes the time to reflect on how the family functions and her own role within the family dynamic; she shares her thoughts and her experience with the families with the group of nurses and trainers, who are professors trained in the PRIFAM.

Method

This qualitative study follows the tradition of interpretive exploratory research (Van der Maren, 1995). The qualitative methodology allows for meaningful reformulation of testimony or experiences (Mucchielli, 1996). The study makes participants (nurses and parents) express themselves *in retrospect* about knowledge they acquired during implementation of the PRIFAM program, i.e. two to three years after the PRIFAM intervention.

Sample

The population under study comprised couples (N= 18) who had had a child with trisomy 21 and their nurse-clinician (N=4) with PRIFAM training.

Data collection

Researchers from the Interdisciplinary Family Research Team (ÉRIFAM) interviewed couples whose child had trisomy 21 and nurses, at home. These semi-structured, individual interviews lasted an average of 90 minutes and were tape recorded and transcribed verbatim; they provided informative data on the practices and opinions of participants (Poupart, Groulx, Mayer, Deslauriers, Laperrière, Pires 1998). Interviewing of nurses dealt with their experience and knowledge prior to the training, and the learning accomplished during PRIFAM training and implementation and after the intervention, on the personal and professional levels. Interviewing of parents covered their experience and knowledge prior to the child's arrival, and the learning accomplished during and after the intervention on the personal, conjugal, parental and extrafamilial levels.

One file was compiled on the parents and another on the nurses. Memos and summary cards were filled out. Notes on the development and execution of the study were kept in a log as the research progressed.

Data coding and analysis

Coding was undertaken with the QRS NUD-IST software, based on themes identified in from the corpus of material and the literature. Knowledge categories and subcategories emerged from the material. Analysis was then undertaken, first in inductive and then in deductive mode. A typology of the learning accomplished by parents and nurses was extracted was produced, based on the work of Artaud (1989).

This learning comprises *theoretical* knowledge defined as new cognitive acquisitions accomplished by the parents; *experiential* knowledge, i.e. knowledge acquired in action, stemming from the interaction between everyone involved in the child's life, and *transformational knowledge allowing each person to modify their life situation*: change emanating from the person themselves as regards values, beliefs and what they knew. This change results in knowledge that is transposed into other situations in the person's life.

The analysis also identified *co-learning* accomplished jointly by parents and nurses. Co-learning means learning together in the same situation, in pursuit of the same goal. Individuals who co-learn are all in a learning situation and acquire respective items of knowledge from each person in an interactive setting (Pelchat & Berthiaume, 1996).

Results

The results of the study show that parents acquire knowledge as they go through the transitional situation into which they are thrust, and during reflection following this experience. The nurses learn both during the PRIFAM training and while applying the program. Below is a description of the knowledge acquired by the nurses followed by a description of that acquired by the parents. This was theoretical, experiential and transformational knowledge. Co-learning by parents and nurses is then presented. Excerpts from the verbatim transcriptions of the participants' remarks illustrate the different types of knowledge.

Nurses' knowledge

Before being trained in the PRIFAM, nurses had only sketchy knowledge of trisomy 21 and family life with a child with a disability.

During their PRIFAM training and while applying the program, they gained theoretical, experiential and transformational knowledge.

Theoretical knowledge

During training, the nurses absorbed new knowledge about the signs of trisomy 21, the characteristics displayed by these children and how to intervene with them, learning a new approach to family intervention. *"I learned about trisomy 21 and acquired theoretical knowledge about family intervention theories".*

Experiential knowledge

Experiential knowledge involved a change in perception regarding families with a child with a disability, the child's characteristics, the way to intervene with families and their own capacity to alleviate the psychological suffering of families. Nurses were given new expertise and skills for dealing with family resources, early stimulation programs and social services. They also gained new experience as a result of dealing with other professionals working with these families.

Through the acquisition of new *experiential* knowledge, they reported that they had changed the way they intervened. *"My vision of families with a child with a disability was not accurate. Now I understand the extent of their emotional needs"*. They found it was not sufficient to give the parents lots of information immediately after they had been told about their child's trisomy 21, because at that point parents are not in a fit state to absorb the information. On the contrary, nurses felt they had to take their cue from the parents. The best time to give them information was when the parents themselves started asking questions; that was when they were best able to assimilate the information.

Although a number of the families' needs are not met by existing resources, the nurses found that the families had major personal resources at hand that enabled them to deal with tough situations. They learned how to relieve the families' psychological suffering and were surprised at its severity compared with physical suffering, something they are more familiar with and know how to treat. They also observed that parental adjustment to the child's disability varied from one family to another.

Spending time with the families, nurses became familiar with the slower pace of development of a trisomy 21 child, and new ways of looking after them or giving them certain types of care. They also developed new attitudes and ways of intervening that were better suited to these families' situation. *"I looked at the father, lost in his thoughts, and the mother who was weeping, and the child lying in the crib at the foot of the bed. I felt I had to bring the father back to reality. So I picked up the baby and asked the father how he was coping. He said lots of people had come into the room, but I was the first to ask him how he was doing"*. By asking questions, the nurses ensured that the parents listened to each other. *"Tell me, what do you think your husband is going through right now regarding the child?"*.

During the intervention at home, parents tended to confide more freely than they did at the hospital. Sometimes the intervention had an effect on the dynamics of the couple, especially when both partners were present and the nurses emphasized the father's role in the family. A nurse recalled one mother saying *"I didn't know my husband was so strong, and could change his mind"*.

Transformational knowledge

Nurses transposed what they learned into practice. Instead of giving families ready-made solutions as they had done previously, they now guided them towards devising their own solutions. Their practice had formerly been largely prescriptive but was now characterized by listening to and respecting the families. Thanks to their new competencies, the nurses found intervening with these families less stressful than before because the burden of responsibility was shared with them. The knowledge they acquired was also transferred to their personal lives. One nurse said she now listened to her husband more and realized the importance of knowing what he felt in a particular situation. She described how she now reacted if there was a problem: *"I'll say come and sit down, there's something we need to talk about. We talk it over and I ask what he thinks, when before I'd have simply told him what we were going to do."*

The nurses found they could now act as a therapeutic tool. Having developed their capacity to provide families with guidance and emotional support and integrated this role, they were now adapting it to their other clienteles. They now realized the full importance of putting these families in touch with other families facing the same problems. And they felt that the parents, in the way they conducted themselves, were an example to them and the extended family.

Some of the knowledge acquired by nurses during the intervention also became integrated into their own personal lives; as a result they evolved as individuals and updated their thinking. They were now more comfortable with difference and realized that monitoring these families had a positive impact on their own personal and family lives.

Parental knowledge

Prior to the PRIFAM intervention, parents knew little about trisomy 21. *"I knew what mongolism was but I'd never heard of trisomy"*. Some had been aware of the stigmatization endured by trisomy children and their families. They felt that people's discomfort in their presence and reluctance to approach them was due to ignorance. Parents acquired knowledge not only from the nurse but also from caring for their child.

Theoretical knowledge

The parents absorbed *theoretical* knowledge about their child's problem, including identifying the signs of trisomy 21 and giving the required care. They found only limited literature was available, with little information about day to day life with a trisomy 21 child.

Experiential knowledge

Through their experience, parents learned to live with a trisomy 21 child. They gained additional parenting skills and came to recognize the child's strengths and those of their spouse, the impact of the extended family on their life, and the role played by the nurse.

They learned to demystify trisomy 21, cope with difference and feel comfortable with it. They came to realize that feeling guilty and wanting to distance yourself from the child are normal reactions. They also learned how to deal with uncertainty and accepted that the intervention does not provide all the answers.

Parents learned to fulfil their role as parents in general, and parents of a trisomy 21 child in particular. Day by day, they became more confident in caring for their child, and learned to adjust to the child's slower pace of development, love them for what they were and nurture their attachment. The nurse's presence helped them build confidence in their own abilities, which in turn helped them to tap into their parenting skills. *"The nurse came to see us often, and she was nearly always available when we called. Each time she saw us, she had more information for us, and it always addressed our concerns"*. Parents became familiar with their child's temperament, strengths and difficulties. *"One day, I said I would stop reading about it because what I read did not relate to what my child was doing. I decided to simply look after*

him, love him and get to know him." With time, parents became more realistic in their expectations and recognized their child's progress. In dealing with their other children, they learned how to handle the reactions of brothers and sisters to the child with a trisomy 21, fostered their feelings of attachment and showed them how to play with the child.

Parents realized how important it was to nurture their own relationship and spend time together as a couple. *"It took time, but the first time I went away with my husband for a few days, I was worried about leaving the child with a babysitter. We'd forgotten how to enjoy each other's company. But after a few short breaks, we rediscovered the fun of being together. And now it's essential to our relationship"*. Each person became aware of their own strengths and difficulties and those of their partner. *"I now realize that he is stronger than I thought and that he can change his mind about important issues."* *"I never thought she could handle such a tough situation, now we know we're together for the long haul"*. Mothers got used to leaving their husbands to look after the child, which relieved them of some of the burden inherent to caring for the child.

Something else the parents had to cope with was the evasive reaction of professionals in the hospital setting. Compared with other professionals, they found the nurse supportive. *"The same nurse always came to see us. She listened to us and she was available. It couldn't always have been easy for her, especially early on, because I cried a lot. She was there, she listened to me and asked questions that helped me to understand the situation and find ways to deal with it. With her, things were easy"*.

Some parents were reassured by the adaptability and sensitivity of their immediate circle, but found that other parents were unable to face up to the new reality. Parents also had to deal with the limited ability of the available resources to provide emotional support. Generally speaking, they were disappointed to find that some physicians blamed all of the child's problems on the trisomy, even if symptoms were related to other causes. *"The pediatrician regarded me as a hysterical mother. When my child kept spitting up, the doctor just said 'well, you know, with trisomy that's how it is, the muscles are looser. Your child is doing this because of the trisomy' "*.

Parents encountered obstacles to their child's social integration. For example, the limitations of certain professionals and their lack of judgment and knowledge about trisomy 21 led parents to seek out other resources to respond to their needs. They appreciated the activities offered by the various associations but found they only offered limited emotional support.

Transformational knowledge

Certain parents learned to act as resources for others, using their new-found knowledge. They also transformed the way they parented their other children in light of this experience. One mother was delighted to find that she felt comfortable with her child and that her husband had gradually become more open to him.

Co-learning

Nurses and parents learned together, as did spouses with each other and parents with their child with a disability. One nurse said *she "learned (from the parents) to listen to families and not give them ready-made solutions but help them find their own: to learn with them"*.

One parent reported *"observing the child's own pace and talking to the nurse, summing up the information provided by the nurse and understanding how the child functioned"*. Another parent mentioned *"learning from the nurses about a step like reminding the child to keep his tongue*

in his mouth". And another said they "watched the nurse proceed by trial and error, looking for and trying out different equipment for tube feeding". One nurse drew the parents' attention to their child's progress. And their contact with the nurse made parents realize that their child was developing faster than they thought. One mother said she had learned about adaptation mechanisms jointly with the nurse: "As we worked with the child together, the things she said that showed me I was grieving for my child's disability, and bonding with him just as I would with another child".

Parents said they accomplished mutual learning with the child. One mother came to appreciate the simple things in life by spending time with her child with a disability. *"Looking after my child and watching him make progress has changed the way I look at life and made me enjoy every moment I spend playing with him. He's taught me that happiness is in the little things".*

Co-learning also occurred between spouses: one couple reported having *"learned about each other's reactions in this difficult situation." "(...) observed each other in a tough situation, saw how the other person reacts and adjusts to the other's expectations".*

Discussion

As this study clearly shows, the theories behind the PRIFAM and the values and beliefs conveyed by the program guide the acquisition of knowledge by the partners. As described by Pelchat (1995) and Pelchat and Lefebvre (2001, 2005), partners learn to recognize each other's strengths and skills and share their knowledge and experience. The conditions for accomplishing this learning also indicate that the partnership relationship forged between nurses and families makes them reflect on their experience and helps to resolve the transitional situation. As evidenced by the knowledge acquired during the intervention, there is an ongoing reflective process and an equal relationship between the partners that leads to reciprocal learning between nurses, trainers and families. The relationship takes root when they first meet and flourishes as the intervention proceeds. As Bouchard (1988), Pourtois (1999) and Sandrine-Berthon (2000) point out, the relationship of trust is built up over time as a result of constant meetings between the partners and the acknowledgement of each person's competencies.

Learning within the PRIFAM framework highlights a form of learning and co-learning based on questioning and reflecting on one's experience. Educating and learning are co-constructions common to the partners involved. By working on themselves and not pre-judging the other person, nurses and parents who took part in the study went on to acquire knowledge. Through this knowledge permeated with each individual's respective perceptions, values and beliefs, nurses develop their role as mediators helping parents to tap into their own skills. Because this is an equal relationship not overshadowed by a power-wielding professional, there is room for decision making by consensus. A transversal reading of the results of this study shows that nurses gave parents time to recover from the shock. They explained the purpose of the meetings and what steps the program would involve.

The results show that the feedback between families and nurses encourages nurses to question the way they intervene. The reciprocal nature of the educational process between nurses and parents led to co-learning.

The nurse was encouraged to explore how she helped the families, recognize the limits of her intervention and the families' own capacity to deal with their situation and find ways to help themselves adapt. Exploring how they intervened also made nurses reflect on certain dimen-

sions of their own personal lives and help to build the parents' confidence about making decisions and caring for their child.

Conclusion

With their philosophy, underlying theories and values and beliefs, the PRIFAM training and program generate theoretical, experiential and transformational learning for nurses and parents alike. Nurses modify their practice and enrich their personal lives. Parents make a positive transformation in their experience as a family with a trisomy 21 child and adjust more successfully, probably because they are monitored by the same nurse throughout, at regular intervals, in a partnership setting. The relationship of trust is introduced by engaging each individual, so that barriers are broken down. The resulting collaboration evolves into reciprocal involvement to which each person is totally committed; this fosters family autonomy.

PRIFAM makes the work done by nurses more satisfying and better tailored to the care needs of families with a child with a disability. The theoretical and philosophical foundations of this program make it transferable to any clientele under severe stress, from the moment a health problem is diagnosed.

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Author notes

Diane Pelchat, Ph.D.^{1,2,3}

Faculty of Nursing
 Université de Montréal
 P.O.B. 6128, Downtown Station
 Montreal (Quebec) H3C 3J7
 Tel.: 514-343-5618
 Fax: 514-343-2306
 E-mail: diane.pelchat@umontreal.ca

Hélène Lefebvre, Ph.D.^{1,2,3}

Faculty of Nursing
 Université de Montréal
 E-mail: helene.lefebvre@umontreal.ca

1. Interdisciplinary Team for Family Research, Faculty of Nursing, Université de Montréal (ERIFAM), Montreal, Canada
2. Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR), Montreal, Canada
3. Inter-network Research Group on Family and Environmental Adjustment (GIRAFE), Montreal, Canada