

Université de Montréal

**Parenting a Child with Leukemia: Mothers' and Fathers' Sense of  
Competence and Orientation towards Uncertainty**

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Université de Montréal  
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Cette thèse intitulée:

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Orientation towards Uncertainty**

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Konstantina Fyta

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## ABSTRACT

Childhood cancer places a heavy burden on all family members by threatening their personal equilibrium and well being. The dual purpose of the study is to explore and describe mothers' and fathers' orientation towards uncertainty and to illustrate parents' perceptions of competence in terms of day-to-day experiences parenting a child with a chronic illness.

Data were collected from a total of 18 couples who completed the Parenting Sense of Competence Scale (PSOC, Johnston & Mash, 1989), the Uncertainty Orientation measures (Sorrentino, Hanna, & Roney, 1992), and a semi-structured interview about their perceptions of competence and experiences of uncertainty.

Findings revealed mothers as most moderate-oriented and fathers as most uncertainty-oriented. No opposite uncertainty-orientation profiles were found among couples. Although findings revealed no statistically significant differences between mothers' and fathers' perception of competence, interview data show maternal dissatisfaction when it comes to parenting and a paternal lack of ability to cope with the child's illness. Results also shed light on the relationship between parents' uncertainty orientation and their perceived sense of competence, as predictors for effective parenting in a family struggling with a chronically ill child.

Overall, the findings are encouraging to elicit further approaches to acquiring information about parents' characteristics and their orientation towards uncertainty. Psycho-educational programs focusing on parents with the aim to improve the parents' sense of competence and mastering uncertainty under life-threatening conditions might be of benefit to the whole family.

Keywords: parenting, coping, uncertainty, sense of competence, leukemia.

## RÉSUMÉ

Le diagnostic de cancer chez un enfant représente toujours une très rude épreuve pour les membres de sa famille et constitue pour eux une menace à leur équilibre et à leur bien-être. La thèse décrit le sentiment d'incertitude des mères et des pères, tout en illustrant la perception qu'ils ont de leur compétence parentale quant au rôle qu'ils jouent auprès d'un enfant malade.

En s'appuyant sur des questionnaires établissant une échelle de compétence parentale (PSOC, Jonhston et Mash, 1989) et sur des mesures du degré d'incertitude des parents (Sorrentino, Hanna et Roney, 1992), on a recueilli des données auprès de 18 couples. Ceux-ci se sont également prêtés à une entrevue semi structurée qui portait sur leurs perceptions de compétence et sur les sentiments d'incertitude qui les habitaient.

L'analyse des résultats révèle que les mères sont plus «modérées» que les pères, alors que ceux-ci s'avèrent plus «incertains» que celles-là. Aucun couple ne présente un profil d'orientation d'«incertitude opposée». Bien que les résultats des questionnaires objectifs ne mettent en évidence aucune différence statistique importante entre les mères et les pères dans la perception que chacun a de sa compétence, les données recueillies en entrevue indiquent une insatisfaction des mères dans leur rôle de parent d'un enfant malade, de même qu'un sentiment de manque d'habileté des pères à s'adapter à la maladie de leur enfant. De plus, les résultats mettent en lumière une corrélation entre l'orientation d'incertitude des parents et la perception de leur compétence, comme variables explicatives d'un «parentage» efficace dans un contexte de maladie chronique.

Dans l'ensemble, les résultats invitent à imaginer d'autres méthodes pour obtenir des informations sur les caractéristiques des parents ainsi que sur leur degré d'incertitude. Des programmes psycho éducatifs à l'intention de parents qui vivent une situation aussi difficile et qui viseraient à améliorer leur sentiment de compétence et à mieux maîtriser leur sentiment d'incertitude, dans un contexte aussi difficile, pourraient être bénéfiques à toute la famille.

Mots-clés: parentage, adaptation, incertitude, sentiment de compétence, leucémie.



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# ***CHAPTER I***

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## ***1.1. Statement of the problem***

### ***1.1.1. Introduction***

Having a child with a serious illness such as leukemia might provoke sustained uncertainty and diminish the parents' sense of competence of parenting. After a child is diagnosed and returns home, parents are faced with an illness trajectory that includes both acute episodes of disease and complicated periods of maintenance therapy. Upon the challenging and demanding situation imposed by such an illness, the family as a whole must deal with the loss of their child's health, as well as the threatening possibility of losing their child. The family must respond to such a crisis event effectively in order to regulate the emotional distress, restore equilibrium and establish its balance.

With respect to parenting, when such adverse circumstances arise in families, not only special skills and knowledge are demanded by parents to bring the situation back to normal, but also much self-confidence regarding their own competence as a parent of a child with a chronic illness. Therefore, it is not surprising if parents experience uncertainty regarding their perception of being a competent parent when trying to cope with such an overwhelming and difficult situation. Since a perception of uncertainty is such an important factor in parents' adjustment and coping, effective interventions should be based on a thorough assessment of both parents' sense of competence and orientation towards uncertainty (Horner, 1997; Santacroce, 2001).

### *1.1.2. The Child with Leukemia*

Acute Lymphocytic or Lymphoblastic leukemia (ALL) is the most common paediatric malignancy, with approximately 2,000 new cases diagnosed in the United States each year. An average of 1,285 children are diagnosed with cancer in Canada, and 239 die each year. Leukemia accounts for over 26% of new cases and 32% of deaths in children (British Columbia Cancer Research Center, 2005; National Cancer Institute of Canada, 2005). ALL is typically diagnosed in preschool-age; the peak incidence occurring between 3 and 4 years of age (Gurney, Severson, Davis, & Robison, 1995; Masera, et al., 1997; Pui, 1997; Waber & Mullenix, 2000). However, over the past twenty years, the outlook for a child diagnosed with leukemia has improved dramatically due to the technological progresses and medical advances in early diagnosis and successful treatments. Thus, this type of childhood cancer that was once considered to be a fatal disease now has a good prognosis for long-term survival rates that can exceed 70% of the identified cases (Clarke-Steffen 1993; Eiser, Havermans, & Eiser, 1995; Fine & Lee, 2001; Fochtman, 1995; Grootenhuis & Last, 1997; Hill, Ciesielski, Sethre-Hofstad, Duncan, & Lorenzi, 1997; Kazak & Barakat, 1997; Kupst, Natta, & Richardson, 1995; Van Dongen-Melman, 1997, 2000). In spite of the fact that survival rates have increased significantly, recent studies document the side effects of modern cancer treatments which negatively contribute to a child's life experience and present a big challenge for parents and their roles as caregivers and their sense of competence (Brown, 1999; Brown, et al., 1998; Van Dongen-Melman, Van Zuuren, & Verhulst, 1998). In other words, current methods of treatment usually cause the child with the chronic illness to experience, even temporarily, physical discomfort posing heavy challenges to the daily routines of families

(Barakat, et al., 1997; Ovenden, 1997). Among the various complications for children undergoing cancer treatment is the number of physical changes they experience. Some side-effects of treatment may be reversible (e.g., short-term effects), such as weight gain or loss, growth problems, hair loss, mouth ulcers and nausea. Along with nausea, children often experience changes in food preferences and disturbances in taste which in turn may affect their eating habits (Eiser, 1998). Other side-effects due to chemotherapy or radiotherapy may lead to lasting physical problems (e.g., long-term effects) such as an increased risk of calcification, endocrine dysfunction, spinal curvatures, sterility and risk of the development of a new malignancy (Eiser, 1990, 1998; Margolin & Poplack, 1997; Muller, Horwitz, & Kuhl, 1998). Indeed, both short and long-term side effects might have a devastating impact on the child's psycho-social adjustment and personality.

From the chronically ill child's point of view, the impact of visible disfigurements, especially loss of hair, is a constant reminder that he/she is not the same child as before. While the side-effects of treatment significantly change the child's body image, a potential loss of self-esteem may also be induced (Brown, 1999; Eiser, 1990, 1998; Van Veldhuizen & Last, 1991). A lack of self-confidence resulting from an altered physical appearance can lead to psychological and behavioral disorders during acute care and long-term follow-ups (Butler, Rizzi, & Bandilla, 1999; Challinor, Miaskowski, Moore, Slaughter, & Frank, 2000; Moleski, 2000). Generally, children with physical impairments are mostly at risk for overall internalizing and externalizing behavioral problems. They may experience significant effects on mood, (e.g., mood swings, depressive mood) emotional liability, anger, denial resistance to treatment, impulsiveness, irritability, hyperactivity, sleep disturbances, increased anxiety and post-

traumatic stress disorders (Robaey, et al., 2000; Sawyer, Streiner, Antoniou, Toogood, & Rice, 1998; Shelby, Nagle, Barnett-Queen, Quattlebaum, & Wuori, 1998; Stokes, 1999). Children with leukemia might demonstrate a delayed social competence, social isolation (including in school relationships), poor motivation, be more withdrawn and introverted as compared to healthy peers. It seems that child cancer survivors are less assertive in social interaction. Therefore, when attempting to relate to peers they are very cautious which makes them often fail (Brown, et al., 1991; Li & Wendt, 1998; Noll, et al., 1997). Consequently, due to the child's difficulty to behave suitably, the relationships and the social interactions with others, especially with parents, are often complicated, altered and negatively influenced. Such problems do not decline over time and adjustment difficulties seem to increase, the longer the child is off treatment (Kazak, et al., 1997; Stuber, Christakis, Houskamp, & Kazak, 1996; Van Dolman-Melman, 1997, 2000; Van Dongen-Melman, et al., 1998).

Another problematic aspect to consider, is that leukemia treatment can adversely affect the development of the central nervous system, resulting in both short-term and long-term cognitive impairments (Armstrong, Blumberg, & Toledano, 1999; Armstrong & Mulhern, 1999; Powers, Vanetta, Noll, Cool, & Stenbens, 1995; Williams, Ochs, Williams, & Mulhern, 1991). Children with ALL who have been treated with cranial radiation or with chemotherapy alone have shown cognitive impairments upon completion of treatment (Rodgers, Horrocks, Britton, & Kernahan, 1999; Schatz, Kramer, Ablin, & Matthay, 2000). Long-term survivors show non verbal neuro-cognitive impairments and learning disabilities in different areas such as reading, spelling and mathematics. Deficits in a variety of memory abilities (e.g., non verbal and verbal short



term memory, visual and auditory memory, mental processing speed) affect the children's ability to concentrate and sustain attention (Hill, et al., 1997). It is interesting to note that while Lockwood's, Bell's, and Colegrove's (1999) findings confirmed that girls with leukemia are at a greater risk for cognitive impairment than boys, especially with respect to speech and verbal memory, Reeb's and Regan's (1998) results revealed that learning disabilities are generally more prevalent among boys diagnosed with leukemia. Concerning perceptual-motor functioning, children with leukemia exhibit poor performance with consistent deficits in fine motor control and visuo-spatial abilities such as visual motor integration, motor speed and coordination (Brown, et al., 1998; Hill, et al., 1997). Due to illness related problems, such as hopelessness, depression and sometimes peer insensitivity, the child with leukemia may be frequently unable to attend school, participate in sports or even to be involved in recreational activities with friends. In fact, school absenteeism and academic deprivation may constitute the major psychosocial sequels of childhood leukemia (Van Veldhuizen & Last, 1991; Williams, et al., 1991). Finally, as Brown (1999) states, these multiple deficits in the neuropsychological and neuro-cognitive areas lead to academic difficulties and poor performance in academic tasks, as well as delayed adaptation and productivity in adulthood.

### ***1.1.3. The Impact of Childhood Cancer on the Family***

#### ***1.1.3.1. The family today and its challenges***

Families today already have a variety of issues, problems and tasks to accomplish. The family's primary function is to provide a setting for the optimal social,

psychological, and biological development of its children, while also continuously offering comfort, guidance and reassurance to its members (Carter & Murdock, 2001; Larson, Goltz, & Munro, 2000; Walsh, 2002, 2006; Yorburg, 2002). An effective and well functioning family is able to respond to the various physical, social, cognitive, psychological, and emotional needs of its members. It also suggests that families are constantly adapting and generating new strategies and patterns of interaction to deal with new challenges. At the same time, every family also gradually develops its own rules and patterns of interactions. Hence, it explains why families may behave in completely different ways under similar circumstances (Ihinger-Tallman, 2005; Ward, 2002). In well functioning families there is a positive interaction among individual members who have expectations, goals and desires and who are also required to perform certain roles (Day, 2003). Then different tasks and responsibilities (i.e., reproduction, nurturing care for the children, promoting social identity and being source of intimacy) can be effectively handled allowing the family to deal with possible changes. In addition, like all systems, anything that affects one part of the family will affect all the other parts. Hence, the experience of one member of the family influences the other members' experiences and overall family well being in positive or negative ways (Crow & Crow, 1988; Masten & Shaffer, 2006; Ward, 2002).

#### ***1.1.3.2. The family with a chronically ill child***

Given the above, if we treat family as an interrelated and complex system, the presence of childhood cancer also affects its members (i.e., parents and siblings) and constitutes a heavy burden that alters family life and equilibrium (Dahlquist, Power, Cox & Fernbach, 1994; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998; Overholser &

Fritz, 1990; Weiss, Marvin, & Pianta, 1997). Such a burden arises from numerous sources including direct care and physical strain, financial concerns and work adjustments, role changes of family members, emotional adjustments and the constant managing of uncertainty (Enskar, Carlsson, Golsater, Hamrin, & Kreuger, 1997; Hendrick-Ferguson, 2000; Martin, Brady, & Kotarba, 1992). Thus, the amount of daily stress that a family confronts and deals with due to such a situation may jeopardize its psychological well being, possibly seriously affecting the parents' sense of competence. At the same time, a serious chronic illness experienced by the child may shed light on the well being of the family and how its members are able to deal with such a challenging situation (Cigoli & Scabini, 2006; Heath, 1996a, 1996b; Ward, 2002).

Since the child's hospitalization, which is rated as the most challenging family event, parents experience stress, increased anxiety and uncertainty due to a number of factors including the unfamiliarity of the hospital setting, the parents' separation from their child, a lack of understanding of the child's critical situation and the inability to care for the child (Alexander, White, & Powell, 1986; Clements, Copeland, Loftus, 1990; Philichi, 1989; Sheldon, 1997). Many studies that focus on parents confirm that the child's hospitalization also calls for changes in the parenting roles. Staying in the hospital with a child, especially during the long period of intensive medical therapy, causes role difficulties for the parents, particularly if there is limited involvement in their child's health care management or if they are not properly informed and guided (Barnhart, et al., 1994; Carnevale, 1990; Neill, 1996; Ogilvie, 1990).

Once the ill child returns home, various changes in family routines become obvious because of the child's special care needs and attention (Sawyer, et al., 1998;

Thoma, Hockenberry-Eaton, & Kemp, 1993; Wittrock, Larson, & Sangren, 1994). Due to the child's with leukemia tendency to be both spoiled and overprotected, proper discipline and balance between focusing too much on the child's disease and other members' needs pose a challenge. A number of difficult decisions need to be undertaken by parents including how to divide the physically and emotionally challenging tasks among them and also how they individually react and adapt to the disease (Van Dongen-Melman, 1997, 2000; Woznick & Goodheart, 2002). Since the role of parents is not a stagnant one, not only are specific knowledge and new abilities needed by both parents, but also, a certain level of flexibility is required in their roles as parents.

Furthermore, the most difficult problem that families of a child with leukemia face is a dependence on the child's disease and treatment modalities (Sawyer, et al., 1998). Families must provide emotional support for their sick child, arrange hospital appointments and help their child cope with disagreeable and painful treatments. Due to these challenges related to assisting the child with leukemia to find its own rhythm and routine within family life, special efforts are required not only from the parents, but also from all other family members, including the grandparents and siblings. From an organizational perspective of family life, particular management is needed as soon as it is possible, in order to promote the child's optimal development. Such management may consist of different arrangements of the home environment, modifications to the child's diet and eating schedule, as well as other possible changes in family routines.

However, being dependent on the child's disease implies much more than trying to re-organize family routines and establish a new style of family life that is supportive of the chronically ill child. Parents also need to seriously consider their life outside of the

family in terms of employment especially if both parents work, in terms of division of tasks and time availability, as well as in terms of their social activities (Woznick & Goodheart, 2002). Consequently, all these enormous responsibilities, difficult planning and significant changes that families experience lead to limitations on freedom of action and lack of free time on the parents' part. Additional problems, such as communication and relationship difficulties among family members are very common (Rolland, 1994; Shapiro, 1983; Walsh, 2002; Ward, 2002). Problems may be experienced in both the marital and the sibling relationships since individual goals and needs have to be put aside. (Daves, 1993; Woznick & Goodheart, 2002). Marital relationship could be affected because of changes in the partners' usual style of life, the different ways parents perceive the illness, and/or how they cope with it (Brotherson & Dollahite, 1997; Wintersteen & Rasmussen, 1997; Vodra & Belsky, 1993).

Furthermore, since childhood cancer is a crisis-life event for the entire family, parents also need to consider the siblings' well being. In fact, studies concerning sibling adjustment made evident distress in terms of emotional, socio-behavioral, academic and physical well being (Brett & Davies, 1988; Cohen, Friedrich, Jaworski, Coperland, & Pendergrass, 1994; Houtzager, Grootenhuis, & Last, 1999). Due to the chronically ill child's health condition and behavioural manifestations, siblings may experience difficulties and fears related to approaching the ill child which in turn may influence siblings' socio-emotional adjustment. Moreover, the parental tendency to overprotect and overindulge the child with illness and to focus all of their attention on this child may contribute, in some cases, to a demonstration of emotional distress and behavioural disorders in siblings (Daves, 1993; Van Veldhuizen & Last, 1991). Siblings easily notice

that the child with illness is treated differently which can cause anger, neglect, guilt, aggressiveness and jealousy possibly resulting in academic underachievement and attention-seeking behaviour (Gallo & Knafl, 1993; Van Dongen-Melman, 2000; Woznick & Goodheart, 2002). However, it is important to mention that siblings may also profit from having a sibling with a chronic condition such as acquiring greater maturity, supportiveness, cooperation and cognitive ability to master situations earlier than their peers (Shepard & Mahon, 2002; Sourkes, 1995).

In sum, families often exhibit a sense of helplessness coupled with disbelief and constant uncertainty when faced with such a circumstance. The severity of the illness in conjunction with the possibility of losing the child impede parents from making predictions about their child's future or making plans for themselves and other family members such as the sick child's siblings. Due to the stressful medical treatments and procedures as well as the unpredictable outcomes of the chronic illness, parents may have to develop new strategies to cope with uncertainty such as living day to day or simply avoiding to think about this detrimental condition (Beresford, 1994; Grootenhuis & Last, 1997; Hendricks-Ferguson, 2000). In a certain way, the steady preoccupation and increased anxiety and concerns of these parents may have a paralyzing effect on the family. It is also important to mention that the parents' perceptions of uncertainty and lack of control over the situation may give rise to new feelings of uncertainty and incapability or doubts regarding the ways they perform their roles as parents (Turner, Tomlinson, & Harbaugh, 1990).

Furthermore, the longer the family deals with the child's chronic illness the sooner they experience both psychological and physical exhaustion such as depressive

disorders, anxiety, worries, exacerbations of chronic health problems, sleep disturbances, and somatic and social dysfunction (Barakat, Kazak, Gallagher, Meeske, & Stuber, 2000; Hung, Wu, & Yeh, 2004; Kazak, et al., 2001). It was demonstrated that a high level of depression influences the ability to provide sensitive care for the child and negatively affects parenting (Eiser & Havermans, 1992; O'Callaghan, Borkowski, Whitman, Maxwell, & Keogh, 1999). Studies on psychological adjustment of children with cancer revealed a significant relationship between maternal depression and childhood adjustment (Sawyer, et al., 1998). In fact, parental distress related to repeated invasive procedures remains relatively high and constant over two to three years of leukemia treatment (Brown, 1999; Kazak & Barakat, 1997). Moreover, the intensity of parental problems have been found to persist at the same level, indicating that many families suffer in silence after completion of treatment (Dahlquist, Czyzewski, & Jones, 1996; Van Dongen-Melman, 2000; Van Dongen-Melman, et al., 1998). A long duration of such a challenging situation can be associated with feelings of frustration, guilt, fatigue, confusion and anger if families do not envision a positive outcome or an end to their child's suffering (Gallery, 1997; Yates, 1999).

#### ***1.1.4. Parents' Uncertainty Orientation and Sense of Competence with an Ill Child***

Since the diagnosis of malignancy, families and especially the parents experience uncertainty about the course and outcomes of the disease, as well as about their child's future (Cohen, 1995; Santacroce, 2001; Sterken, 1996; Van Dongen-Melman, Hahlen, & Verhulst, 1995). For most parents, concerns and worries over various aspects of their child's development become an integral part of daily life. In other words, parents are

mainly uncertain about the course of their child's illness and its long term prognosis, medical treatments, long-term survival chances, physical and emotional after-effects of leukemia and how they can support their child in coping with the disease (Enskar, et al., 1997; Hendricks-Ferguson, 2000; Last & Grootenhuis, 1998).

Uncertainty about the child's illness trajectory may give rise to sustained parental uncertainty about how to best maintain their parental role and a sense of competence. Parental uncertainty appears to be notably acute and very intense during the diagnosis phase and may alter the parents' perception of their competence as parents. Since parents consider themselves as main contributors to the well being of their child by providing the majority of physical care and psychological support, they also feel that they know their child best. Yet, parents are expected to relinquish their role to the hospital specialists, which often generates a parental conflict possibly making the relationship with the professional staff difficult (Daves, 1993; MacDonald, 1996; Wright, 1993). Often, parental uncertainty continues after hospital discharge because there is still lack of clarity about what to do or what not to do, which leads to intense preoccupation and worry about their child's situation and affects parents' management of usual family life (Coleman, et al., 2002; Eiser & Havermans, 1992; Santacroce, 2001). In addition, as a result of their uncertainty, parents may lose confidence in their ability to perform other essential parental tasks. Hence, it is worthwhile examining more closely feelings of uncertainty among parents who now deal with a child with illness at home.

Furthermore, given the challenges of parenting a child with illness under uncertain conditions, it is necessary to consider the parents' cognition, such as the parents' perceived sense of competence in parenting. The parents' sense of competence is



defined as that person's perceived effectiveness or competence as a parent to recognize, interpret and respond to their children's cues (Grusec, Hastings, & Mammone, 1994; Holden, 1997; Ohan, Leung, & Johnston, 2000; Teti, O'Connell, & Reiner, 1996). Children who are at risk or affected by a chronic disease such as leukemia, may express incomprehensible and ambiguous cues which in turn foster feelings of inefficacy among parents. Precisely, parents who believe they do not have the ability to parent successfully become worried, emotionally aroused and unmotivated to perform parenting tasks (Grusec, et al., 1994). Conversely, it is believed that individuals who feel good about themselves as parents and who also have a cohesive sense of competence are more effective parents (Ohan, et al., 2000; Partridge, 1988). Studies have revealed that parents of children with a chronic illness tend to have a lower sense of competence than parents of children who are less challenging (Coleman, et al., 2002; Rodrigue, Geffken, Clark, & Hunt, 1994). Research has shown that efficiency in managing such a challenging situation and promoting a family's well being depends significantly on parental coping strategies (Elliott-Brown & Barbarin, 1996; Horner, 1997). Some empirically focused studies have also assessed the coping of both mothers and fathers, while others focused specifically on mothers (Grootenhuis & Last 1997; Sterken, 1996).

Given the fact that adaptation of families to such challenging situations may be greatly influenced by the parents' self-perceptions and sense of competence, parents need to believe in themselves and in their abilities. This underlines the importance for health care professionals and educators of parents to gain knowledge and a clearer understanding of the parents' sense of competence and their orientation towards uncertainty and coping while facing their child's chronic illness. In the absence of such

considerations, family functioning may further deteriorate and adversely affect collaboration and effective work with other concerned parties such as the hospital, the health care services and the school. Parents' sense of competence needs to be carefully addressed since it may also affect the family as a whole and its ability to cope with and come to terms with the illness of their child.

### ***1.1.5. Problem Statement***

#### ***1.1.5.1. Pertinence of research study***

In spite of the challenging situation experienced by families with special needs children, limited research has focused on contemporary parents and their experiences of parenting over time a child with a chronic illness (Kristjanson & Ashcroft, 1994; Kruger, 1992; Lee & Guck, 2001; Svavarsdottir, 2005). Studies focusing on parenting have not systematically examined how the parents' sense of competence itself is influenced by challenging situations, such as having a child with a chronic illness and the experienced uncertainty (Kazak, Boyer, Brophy, Johnson, & Scher, 1995; Kochanska, Clark, & Goldman, 1997; Wenniger, et al., 2000).

Despite the fact that parenting self-esteem has generated considerable interest, parenting perceptions of efficacy and satisfaction among parents who have a chronically ill child have not often been studied (Coleman, et al. 2002; Rodrigue, et al., 1994). Furthermore, although research findings confirm differences between mothers' and fathers' reactions and coping with childhood cancer (Woznick & Goodheart, 2002), limited research has examined the similarities and differences in mothers' and fathers' perceptions of competence and ways of performing their caregiving roles and family

related tasks under such challenging conditions (Eiser, et al., 1995; Knafl & Zoeller, 2000; Mercer & Ritchie, 1997).

On the other hand, it is indubitable that children and their families have to change and adapt to this new detrimental and adverse circumstance. It is known as well that the process of adaptation is very different across families (Birenbaum, 1990; Brown, 1999; Hoekstra-Weebers, et al., 1998). How well the family copes with the cancer experience is reflected in the extent to which the family members are able to function as individuals and as a unit during such an experience. Questions can arise such as: How can these particular families be better helped through professional support groups and educational outreach programs when so little is known about such parents' orientation towards uncertainty and their perceptions of competence? In addition, since uncertainty as a perceptual variable influences response to stress, further research is needed to explore the kinds of uncertainty families may face and how such uncertainty may affect the parents' sense of competence in the context of a chronic illness.

Since parental education remains an important component of many intervention models for at risk families, it must be considered very important to target family's needs and provide resources so that all family members (i.e., mothers-fathers-siblings-child with illness) may be reached (Bonney, Kelley, & Levant, 1999; Gavin & Wysocki, 2006; McCartney, 2006; Lamb & Laumann-Billings, 1997; Lobato, 1990; Wysocki & Gavin, 2006). Succeeding at such a challenge might have the effect of promoting family adaptation and well being, and enhancing collaboration among family members. It is also important to consider, however, that even when educational programs or services are

available, problems still can arise when the parents' orientation towards uncertainty and perceptions of competence under critical situations are not properly understood.

Although the severity of the disease and the complexity of the medical treatments will make professionals most likely focus on the child with illness, still a central issue remains the ability of the parents and the professionals both to collaborate in an active and successful way. It is worthy to mention that the role of a professional who also takes care of the child is very demanding and time consuming. The lack of understanding of professionals (i.e., school teachers, health care specialists, parents' educators) about the ways parents perceive themselves and their roles and their experienced uncertainties and fears may prevent them from providing an appropriate support to these families. Professionals in the health education, social services, and school community could help more effectively if they are taught how to understand and be aware of the parents' preferences to facing uncertainty and their related difficulties in perceiving themselves as competent parents. Since education law (PL 99-457, 1986) prescribed interdisciplinary collaboration among parents and medical, psychological, and educational professionals to develop educational plans for children with medical chronic conditions; such a lack of knowledge poses an important problem in answering specific family needs and promoting a constructive cooperation between the families and other institutions (Worchel-Prevatt, et al., 1998).

Furthermore, research has revealed evidence that sense of competence beliefs have proven to be a very powerful determinant of an individual's behaviour (Bandura, 1982, 1986, 1989, 1995, 1997, Kruger, 1992; Schwarzer, 1992). Therefore, education interventions focusing solely on an increase in knowledge are insufficient to induce

behaviour change. At this point it should be interesting to consider the possibility for the implementation of a more comprehensive education program for parents that will focus on the enhancement of parents' sense of competence beliefs by increasing the likelihood of mastering uncertainty experience.

In this study an investigation of the parents' experiences with parenting their child with a chronic illness will focus upon the association between their sense of competence and uncertainty orientation. The aim is to shed light on these variables in order to help professionals consider parents as active participants in the planning and execution of programs implemented in the future rather than as "passive clients" waiting to receive services.

#### ***1.1.5.2. Research questions***

The dual purpose of this study is to describe mothers' and fathers' sense of competence and to explore their orientation towards uncertainty in parenting in a family with a child with a chronic illness. The following four research questions are investigated:

- 1) What is the parents' sense of competence within their family that now includes a child with chronic illness?
- 2) What is the parents' orientation towards uncertainty?
- 3) Are there any differences due to gender in terms of the parents' uncertainty orientation and their sense of competence? and
- 4) Are there any relationships among the parents' uncertainty orientation and perceptions of competence as parents in a family with a child with chronic illness?

### ***1.1.6. Summary***

In sum, one can assume that parents live and cope with continued uncertainty when it comes to parenting a chronically ill child. Yet, as discussed, there are gaps in the literature regarding the following issues: parental sense of competence under uncertainty; parents' orientation and/or interpretation of experienced uncertainty when parenting a child with leukemia; differences and similarities between mothers' and fathers' perceptions of uncertainty and competence, and the impact of uncertainty on parents' perceptions of competence, four issues explored here. In the next chapter we describe in greater detail the literature pertaining to these issues.

## **CHAPTER II**

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## ***2.1. Review of literature***

### ***2.1.1. Chapter Overview***

The purpose of this chapter is to contextualize the proposed study in the current literature pertaining to the parental sense of competence and perceived uncertainty when parenting a child with leukemia. The literature review is organized into three sections. The first section contains an overview of the literature concerning uncertainty and coping, a definition of these concepts, as well as a discussion of the literature describing how parents actually cope with uncertainty. Next, a review of the literature related to the perception of competence among mothers and fathers and the different factors influencing a sense of competence is presented. In the third section, an overview of the literature on parental roles and gender differences in parenting is provided.

### ***2.1.2. Uncertainty and Parenting***

#### ***2.1.2.1. The concept of uncertainty***

In essence, uncertainty is defined as an undesirable perceptual and cognitive state or a response to an ambiguous and unpredictable event created when such an event cannot be adequately structured or categorized due to insufficient cues (Berger & Burgoon, 1995; Cohen, 1993a, 1993b; Hilton, 1992, 1994; Loveys, 1990; Mishel, 1988, 1990, 1991; Murray, 1993; Selder, 1989; Tomlinson, 1996). The notion that uncertainty constitutes a significant characteristic of people's lives in the 21st century is not new (Merry, 1995). Examples come from studies in theories of communication and uncertainty management (Albrecht & Adelman, 1987; Berger & Calabrese, 1975;



Brashers, 2001; Cherlin, 1980; Ellis, 1992; Gao & Gudykunst, 1990), medicine and medical decision making (Burszajn, Feinbloom, Hamm, & Brodsky, 1990; Fox, 1980, 2000; Katz, 1984), risk management, and self-organization research (Roney & Sorrentino, 1995a, 1995b; Sekidides & Strube, 1997; Sorrentino, Hewitt, & Raso-Knott, 1992).

Uncertainty is multifaceted, interconnected and temporal (Brashers, 2001; Hilton, 1992, 1994), and may take many forms such as: uncertainty regarding the self (i.e., a person's beliefs, values and behaviors), others, and in terms of features of a situation (i.e., environmental ambiguity, procedures and rules). Although the perceptive component of uncertainty tends to be an intuitive process, the cognitive component entails an interpretive process, implying the development of thought in response to a threatening stimuli (Mishel, 1984, 1988; Sorrentino, 1996; Sterken, 1996).

When looking at the literature on how people deal with a serious illness much research examined the notion of uncertainty. In fact, the concept of uncertainty is widely studied and recognized as a key factor in the management of a chronic illness (Cohen, 1993a, 1993b; Cohen & Martinson, 1988; Ford, Babrow, & Stokes, 1996; Heath, 1996a, 1996b; Landis, 1996; Yatcheski, 1988). In many studies, uncertainty is associated with stressful experiences, anxiety, vulnerability and pessimistic perceptions due to stress experienced due to illness and relapse, such as the threat of cancer recurrence, lack of hope and lack of support (Christman, 1990; Christman, et al., 1988; Hilton, 1992, 1994; Turner, et al., 1990). Also, uncertainty in illness is mainly perceived as a negative state and danger disturbing personal well being and equilibrium, whereas certainty and

predictability are considered to be positive and desirable (Mishel, 1988; Weiner & Dodd, 1993; Weitz, 1989).

While conceptually, there are many ways in which the relationship between uncertainty and illness has been examined, there is agreement in terms of the definition of uncertainty in the literature (Barbrow, Kasch, & Ford, 1998; Mast, 1995). Hence, experienced uncertainty due to illness is defined as the inability to determine the meaning of illness-related events (Bailey & Nielsen, 1993; Sharkey, 1995). Accordingly, Lazarus and Folkman (1984), in their encompassing work on stress and coping, defined uncertainty as the person's "mental confusion", referring to an unclear or ambiguous situation that limits one's ability to adequately appraise and cope with a given situation. In addition, Hilton (1992) and Cohen (1993a, 1993b) define uncertainty as a cognitive and perceptual state that exists on a continuum and changes over time.

Uncertainty in illness has been mainly developed as a research construct by Mishel (1981, 1984, 1988, 1990, 1991), leading to a theoretical model of uncertainty appraisal and coping based on studies of Lazarus and Folkman (1984). Furthermore, situational factors related to the actual experience of illness, the nature of medical treatment, and anticipated illness outcomes and social support also have important effects on the manner uncertainty is experienced (Mishel, 1988). Mishel's conceptual model emphasizes a person's need to "make sense" of the situation and all situational factors and refers to the cognitive processes involved in that interpretation. Following the appraisal of uncertainty as a natural and inherent part of reality and as a dynamic and evolving process that changes over time, different coping strategies are typically adopted

by persons that then mediate the person's appraisal and adaptation to that situation (Mishel, 1990).

In Mishel's theoretical approach, uncertainty consists of the following characteristics: a) ambiguity about the nature of the illness; b) complexity in relation to the various treatments possible and the health care system in general; c) lack of sufficient information concerning the diagnosis; and d) unpredictability about the course and prognosis of the disease. When events are presented as ambiguous, complex, lacking information and unpredictable, a state of uncertainty may be created due to the objective nature of the events or to due to a person's inability to interpret such events (Mishel, 1981, 1983, 1988; Mishel & Braden, 1988). It is noteworthy to mention that in Mishel's original theoretical model, uncertainty was viewed more as a particular state rather than as an evolving process that changes over time. Yet, Mishel (1990) reformulated her theory with an orientation towards a more dynamic model better accounting for its complexity and instability. In Mishel's (1990) new theoretical reformulation, uncertainty in illness is now viewed more as a positive natural phenomenon, rather than a negative state which provides the ability to re-evaluate life after a crisis event toward various alternatives and choices.

Another explicative framework of uncertainty that originated from a multitude of theories in social psychology is the so called "Uncertainty Orientation" theory by Sorrentino (Sorrentino & Roney, 1986, 1999, 2000; Sorrentino, Roney, & Hanna, 1992; Sorrentino & Short, 1986). Uncertainty Orientation is defined in terms of the different ways that individuals seek out and deal with information. According to Sorrentino and Roney (1999, 2000), uncertainty is related to the self and to the individuals' abilities and

motivation to accept or to avoid new information, and hence, the concept of uncertainty orientation has to be examined through personal spheres and phases of the life trajectory. Also, considering the fact that a situation may entail certainty and/or uncertainty about the self and the world, individual differences in terms of uncertainty orientation are expected to play a significant role in determining behaviour (Hodson & Sorrentino, 1997; Sorrentino, Hewitt, & Raso-Knott, 1992).

In Uncertainty Orientation theory, uncertainty is also defined as a cognitive and motivational variable. It is assumed that individuals use a cognitive schema in order to understand the self and the surrounding environment, and when uncertainty is experienced, individuals will be motivated to reduce it. (Sorrentino & Hewitt, 1984). In fact, Sorrentino's Uncertainty Orientation theory proposes the integration of both cognitive and motivational factors that then predict behaviour. The theory also focuses on an individual's tendency to learn something new about the self, the others or the surrounding environment (Sorrentino, Hanna, Holmes, & Sharp, 1995; Sorrentino, et al., 1992).

Sorrentino's theory about uncertainty orientation combines Kagan's and Rokeach's work on uncertainty and aims to explain uncertainty resolution in different circumstances of daily life. Uncertainty Orientation theory affirms that the resultant value of a given uncertain circumstance consists of two types of values; the informational value (learning new things as opposed to being uncertain or confused) and the affective value (feeling good as opposed to feeling bad). Furthermore, understanding the motivation underlying each dimension (i.e., "finding out" and "feeling good"), requires considering both approach and avoidance in one's behaviour to resolve uncertainty.

According to that model, there are two types of people at opposites from one another. On the one extreme, we have people with an uncertainty orientation linked to the “informational value” and who show a preference to approach new knowledge on the one hand and to avoid ambiguity on the other (Hodson & Sorrentino, 1997; Roney & Sorrentino, 1995a, 1995b). Thus, resolution of uncertainty results not in the search of meaning but rather in the seeking of information (i.e., clarification, self-assessment and self-verification). Thus, uncertainty-oriented individuals are motivated to engage in uncertain situations and resolve uncertainty by finding out new and unpredictable information. Uncertainty-oriented individuals are also curious about the unknown and highly tolerant of ambiguity. Therefore, uncertainty-oriented individuals consider uncertainty as an opportunity to learn something new about themselves or the world. In contrast, at the opposite end of the continuum, certainty-oriented individuals prefer the known and do not engage in potentially threatening situations; they seem to have developed a basic mistrust of the world and lack a sense of autonomy. Because of their low tolerance for ambiguity, they are highly motivated to remove uncertainty from their lives and to maintain clarity. In this case, uncertainty is perceived as dangerous and as to be avoided (Sorrentino, 1996; Sorrentino, Bobocel, Gitta, Olson, & Hewitt, 1988).

Furthermore, uncertainty orientation as an individual variable was also considered in relation to self-evaluation concerns such as self-assessment and self-verification (Roney & Sorrentino, 1995a, 1995b). The authors suggest that uncertainty-oriented individuals are persistent on self-assessment (i.e., learning something new about themselves). In contrast, certainty-oriented individuals are more motivated by self-verification purposes (i.e., avoid uncertainty and maintain existing beliefs about the self).

One can assume that both Mishel's (uncertainty in illness) and Sorrentino's (uncertainty orientation) theoretical frameworks provide a valid contribution to the explanation of human behaviour under uncertain conditions despite some differences in terms of the authors' conceptual perspectives. For the purpose of the present research study Sorrentino's theoretical framework will be adopted to identify uncertainty orientation in parents linked to their sense of competence as caregivers and also to describe differences in individual behaviour in terms of perception and coping with uncertainty.

#### ***2.1.2.2. Coping with uncertainty***

Following a disruption of a person's reality, individuals adopt diverse coping strategies to resolve or reduce uncertainty and to adapt to a new way of life (Hilton, 1992; Merry, 1995; Sorrentino, et al., 1995; Wurzbach, 1992; Wiener & Dodd, 1993). According to Lazarus's and Folkman's (1984) theory, coping is defined as constantly changing cognitive and behavioural efforts to deal with specific external and/or internal demands that are appraised as challenging or exceeding the resources of a person. Similarly, Murray (1993) states that the coping process is characterized by change in thoughts and behaviour over time as a consequence of continuous reappraisals of the person-environment interaction.

According to Weitz (1989), two basic strategies may be adopted in order to cope efficiently with uncertainty: vigilance and avoidance. In exercising vigilance, individuals attempt to reduce uncertainty by seeking knowledge and information and doing comparisons. People seek information from a variety and types of sources to add

knowledge they lack or to validate or disconfirm their actual state of beliefs to decrease uncertainty (Brashers, 2001). Alternatively, with avoidance, individuals cope with uncertainty by protecting themselves against unpleasant knowledge and avoiding any contact with persons with pessimistic attitudes. In particular, the avoidance behaviours include “direct information avoidance”, “selective attention” and “social withdrawal” (Mishel, 1984, 1988). In spite of the fact that the vigilance and the avoidance strategies may appear contradictory to one another, they are linked by a common goal: the construction of a normative framework that helps individuals explain their situation to themselves. Such a framework makes the world appear predictable and provides individuals with both, a sense of understanding of what has happened and alternatives or choices to live their lives afterwards.

Accordingly, Padilla, Mishel and Grant (1992), and Mishel (1983, 1988, 1990) suggest that when uncertainty is perceived as danger or as an opportunity, problem-focused and/or emotion-focused strategies are adopted to mediate the relationship between appraisal and psychological adaptation among individuals. Problem-focused strategies are related to defining the difficult situation and its causes, finding alternative solutions, seeking understanding, weighing them in costs and benefits, and taking action. On the other hand, emotion-focused strategies (i.e., wishful thinking, keeping faith, disengagement, redefining the situation) consist of those activities that serve to regulate and decrease negative emotions such as anxiety and stress (Van Veldhuizen, 1991). Furthermore, when uncertainty is perceived as an opportunity, the so-called “buffering” methods will be used, impeding new input of stimuli that may change such a perception of uncertainty and destroy the individual’s belief in a positive outcome. Such strategies

include selective ignoring (i.e., focusing on positive aspects of the “unpredictable”), and reordering priorities (i.e., reorganizing and making changes in life style). Sharkey (1995) agreed with Mishel’s positive appraisal of uncertainty and added that in certain circumstances uncertainty may be evaluated as an opportunity to normalize life. Normalization consists of engaging in activities to achieve a life style similar to that experienced before the arrival of a threatening event, giving a person hope and continuity in terms of prior values. Sharkey (1995) also discussed the normalization process of a family, the tendency to define their life as essentially normal and their engagement in behaviours that demonstrates normality to others. Both Kruger (1992) and Selder (1989) added that normalization not only contributes to reducing uncertainty but also to significantly increasing the sense of competence.

Similarly, Sorrentino’s Uncertainty Orientation theory (Sorrentino & Roney, 1986, 1999, 2000; Sorrentino & Short, 1986), deals with either resolving uncertainty or maintaining clarity about the self and/or the environment. People’s coping strategies are related to their uncertainty orientation and are constituted along a continuum. In particular, those individuals who consider uncertainty as a challenge are situated at one end of the continuum, whereas at the other end are those who find uncertainty as something to be avoided. It is assumed that both uncertainty and certainty-oriented individuals are often confronted with uncertain situations (Sorrentino, et al., 1992). The critical difference is how they respond to these situations (Sorrentino, 1996; Sorrentino, et al., 1988). Uncertainty-oriented individuals are those who have been rewarded for autonomous exploratory behaviour. Their approach to resolving uncertainty has become part of their way of thinking about the world (Sorrentino, 1996; Sorrentino, et al., 1992).



Uncertainty-oriented individuals follow current models of information processing, and show a high capacity for formal thinking and ability to confront uncertainty. They are attracted to hypothetical-deductive thinking that provides them with an opportunity to maximize positive information (Sorrentino & Roney 1986, 1999, 2000). In other words, they are assumed to be success-oriented people who are primarily motivated to seek clarity through mastery of uncertainty. On the other hand, certainty-oriented people develop cognitive schemas for safe situations and are attracted to concrete thinking that deals with the real and the known. They ignore changes to existing ways of knowing and try to maintain clarity given their confidence in their way of thinking. Certainty-oriented individuals are threatened by any circumstance that creates confusion and ambiguity. Consequently, they are attracted to predictable situations and exercise an authoritarian way of knowing, with a high resistance to alternatives or changes. Obviously, for certainty-oriented people with a low tolerance for ambiguity uncertainty has to be avoided or removed when it is experienced. It is also noteworthy that uncertainty orientation is assumed to be time-linked and relatively stable throughout life (Sorrentino & Roney, 1986, 1999, 2000). This means that uncertainty-oriented people are assumed to be, and to remain future-oriented when they seek out new concepts by exploring the unknown, in contrast, certainty-oriented individuals are assumed to be past-oriented with a strong adhesion to what is already known. Finally, it can be expected that if the situation entails ambiguity and confusion, uncertainty-oriented individuals will be motivated to confront uncertainty, whereas certainty-oriented people will be motivated to avoid that situation. It is also important to mention that Sorrentino's statements concerning individual behaviour toward uncertain conditions are consistent with previous

theories such as Uncertainty Reduction theory (Berger & Bradac, 1982; Kellerman & Reynolds, 1990; Wurzbach, 1992) and Self-efficacy theory (Bandura, 1982, 1986, 1989, 1995, 1997). Both Uncertainty reduction theory and Self-efficacy theory state that high uncertainty stimulates an intense behaviour for seeking information and results in the mobilizing of a variety of behavioural responses. Individual differences in efficacy beliefs and availability of coping resources also come into play.

### ***2.1.2.3. Parents' perception of uncertainty and coping within a chronic illness in family***

In the context of a family's adjustment to a chronic illness of one of its children, coping with uncertainty entails a very complex process, a process of coping that will also change over time as the nature and source of uncertainty change (Christman, 1990; Cohen, 1995; Hilton, 1992; Mishel, 1984, 1988, 1990; Weitz, 1989). Uncertainty due to experienced illness in a family can generate confusion, ambiguity, heightened anxiety, depression and helplessness, and is likely to interfere with the family members' cognitive functioning necessary for appraisal of the situation (Hilton, 1992). In Wiener's and Dodd's (1993) study on families with cancer patients, uncertainty was associated with a "loss of control". A number of different strategies were adopted by individuals to lessen the impact of uncertainty and regain control. These strategies consisted of seeking comparisons, developing expertise, setting goals, choosing a supportive network and taking charge of the situation. Additionally, as Levine and Wiener (1989) state, coping strategies such as "having/being in control" and "feedback" reduce uncertainty, especially in an uncontrollable situation. Therefore, the strategy of "having/being in control" may decrease uncertainty by eliminating or regulating the duration and intensity

of threatening stimuli. Similarly, a “feedback” strategy may decrease uncertainty if sufficient information about the illness is provided. Thus, it is clearly understandable that the key to manage uncertainty in family also entails reaching a sense of control and mastery of the situation.

With respect to parental uncertainty and coping with a child’s illness, parents have to deal with changes in family and personal life such as role alteration, work arrangements, social isolation, and financial concerns. Parents also experience increased uncertainty about their child’s health and future outcomes, and a heightened sense of vulnerability, fear, and self-doubt concerning the responsibility for care of the child (Enskar, et al., 1997; Last & Grootenhuis, 1998; Maclean, 1999; Manne, et al.,1996).

According to Mishel and Braden (1988), and Mishel (1983), parental uncertainty regarding illness consist of four characteristics:

- a) ambiguity concerning the illness;
- b) lack of clarity resulting from incomplete explanations or lack of comprehension;
- c) lack of information about the illness and its treatments and;
- d) unpredictability about the illness outcomes and the parental role.

Specifically, ambiguity, the most general characteristic of uncertainty, results from the inability to place the event within a comprehensive gestalt, possibly generated by the medical technology, the complex illness related treatments, and the unexplained illness symptoms. Lack of clarity, a second characteristic, is mainly a result of the incomplete explanations that are given. Parents often have difficulties understanding the

provided information due to their inexperience, possibly limited education, psychological distress and physical exhaustion. Lack of information about the illness and its treatments, the third characteristic, results from unshared and/or unknown information regarding illness diagnosis or efficacy of illness related treatments. Therefore, due to the lack of known information, parents are unable to formulate statements of probability and future outcomes. Unpredictability, as a fourth characteristic of uncertainty centers on concerns related to the child's illness and the parental role. Parents can lose confidence in their ability both to adequately evaluate their child's health and to perform other essential parental roles. They are usually not aware of how the illness will be managed or what daily life will be like in light of the diagnosis and its treatment. Cohen's (1993a, 1993b, 1995), Cohen's and Martinson's (1988), and Murray's (1993) studies in the context of a chronic illness, have confirmed that the diagnostic phase was the period during which parents expressed the greatest uncertainty about the specific nature of the illness, its course, and its prognosis. However, uncertainty persists even after a hospital discharge and spreads to every aspect of family life compromising parental coping abilities, adjustment to illness and management of family life (Lazarus & Folkman, 1984; Mishel, 1983; Santacroce, 2001; Tomlinson, 1996). According to Cohen (1993a, 1993b), uncertainty appears on six interactive aspects of daily life where parents are required to cope: time, social interaction, awareness, information, illness and environment. Concerning time, parents had adopted the strategy of taking "one day at a time" which helped them make plans, improve relationships, and reduce uncertainty. Management of awareness entails the use of cognitive strategies such as avoidance of thinking about illness, keeping busy, and keeping to routines, and daily tasks, that would extenuate the

threat of uncertainty. In order to maintain, disperse, or in some circumstances raise uncertainty, parents might deal with information by adopting an information-seeking behaviour, or by reducing or transforming existing information, depending on parents' personality and beliefs.

With respect to parents' gender differences in coping, although maternal responses have been frequently equated with paternal responses, men and women cope differently within such a challenging situation. Some empirical studies point out that mothers of chronically ill children express the need to know about the ambiguous future and master uncertainty through knowledge such as seeking information from different sources, searching for answers and being persistent about asking questions (Horner, 1997; MacDonald, 1996; Woznick & Goodheart, 2002). Additionally, in their work on living with childhood cancer, Woznick and Goodheart (2002) state that mothers mainly feel and express the need for support and respond to such a stressful situation through nurturing themselves and their children and creating contacts with a larger social group.

Concerning fathers' coping, Cayse's study (1994) points out that the coping strategies used by fathers consist of problem-focused activities such as seeking information, and emotion-focused strategies such as prayer. Similarly, McKeever (1981), stated that fathers had unique needs and concerns regarding gaining more knowledge about the disease, having more time for leisure activities, and requiring more support. Consequently, fathers seemed to manage efficiently by mobilizing hope, maintaining a clear sense of self-worth and curbing negative emotions. Furthermore, Sterken (1996) in his study of uncertainty and coping among fathers of children with cancer, found that younger fathers used coping styles such as optimism (i.e., positive thinking, comparisons,

and outlook), evasion (i.e., avoidance activities such as going for drives, consuming drugs, putting energy into work) and emotion (i.e., expressing emotions and feelings).

In spite of the fact that uncertainty has been examined by numerous studies on coping with stress (Lazarus & Folkman, 1984), uncertainty and illness (Cohen 1993a, 1993b; Maclean, 1999; Sharkey, 1995) and perceived control and helplessness (Bandura, 1986, 1995, 1997), there is little research with a focus on the relationship between experienced uncertainty and parental sense of competence when parenting a child with chronic illness.

### ***2.1.3. Sense of Competence and Parenting***

#### ***2.1.3.1. The sense of competence construct***

Perceived sense of competence is defined as people's beliefs and judgments of their capabilities to accomplish a certain level of performance whatever the fundamental skills might be (Bandura, 1997; Coleman & Karraker, 1997; Donovan, Leavitt, & Walsh, 1990; Lovejoy, Verda, & Hays, 1997; Raver & Leadbeater, 1999; Teti & Gelfand, 1991). In other words, a perceived sense of competence is not a measure of the skills a person has, but an estimation of what he/she can do under different circumstances with whatever skills he/she possesses (Bandura, 1989, 1995, 1997).

Nevertheless, given the complexity of the sense of competence construct, it is extremely important to make a conceptual distinction between "competence" and "sense of competence". From an objective point of view, competence is judged by whether or not a persons' performance is coherent and conforms with societal rules and expectations. In contrast, subjective competence refers to a persons' appraisal of how well they judge

their abilities to perform a role comparative to their expectations of that role (Sabatelli & Waldron, 1995).

With respect to the “sense of competence” construct, Bandura’s Self-efficacy theory (1982, 1986, 1989, 1995, 1997) employs the concept of “self-efficacy” instead of “sense of competence” to explain how individuals function and perceive themselves. Specifically, the “self-efficacy” construct, proposed by Bandura refers to the beliefs in one's ability to perform successfully a particular behaviour. Based on Bandura’s theory (1989), four factors can increase people’s beliefs concerning their personal abilities. Firstly, through mastery of experiences that require cognitive, behavioural and self-regulatory tools to cope with ever-changing life situations, one may develop a stronger sense of personal competence (Coleman & Karraker, 1997; Ozer & Bandura, 1990; Raver & Leadbeater, 1999). The second manner to strengthen people’s beliefs is through vicarious experiences. For example, seeing individuals comparable to oneself succeed through perseverance raises observers’ beliefs that they also possess the capabilities to master analogous activities. The more a person feels the other is similar to oneself; the more the former’s successes and failures will be influential. Verbal persuasion constitutes the third mode of increasing people’s beliefs. That is, individuals who receive verbal feedback that they are capable of mastering the given activities, are likely to mobilize great effort when new problems arise. Persuasive enhancement lead people to try hard enough in order to succeed. Hence, self-affirming beliefs may promote development of skills and a sense of competence (Bandura, 1995). So far, the notion of sense of competence involves a generative capability in which motivational, cognitive, and behavioural abilities must be organized into courses of action in order to exercise control

over given events as well as to regulate thought processes and psychological states (Bandura, 1989, 1997; Raver & Leadbeater, 1999).

Since life can be full of disappointments, frustrations and impediments, perceptions of one's own competence are critical to individual functioning (Bandura, 1986; Markus, Cross, & Wurf, 1990). A perceived sense of competence may serve as a personal resource but also as a vulnerability factor (Coleman, et al., 2002; Jerusalem & Mittag, 1995). When considering sense of competence as resource, it is assumed that people with a high sense of competence trust their own capabilities to master different types of situational demands. They tend to interpret demands and troubles more as challenges than as threats or uncontrollable events. High perceived sense of competence enables individuals to face stressful situations with confidence, feel motivated by physiological arousal, and judge positive events as caused by effort and negative events as due primarily to external circumstances. In addition, when a person feels a sense of competence, it is typically carried and maintained by a set of self-relevant internal structures that can facilitate competent performance in a certain domain. Thus, sense of competence is a key factor in the ability to protect one's self from the effects of stress, and perhaps even in staying healthy and preventing disease (Markus, et al., 1990). In contrast, considering sense of competence as a vulnerable factor, individuals who exhibited a low sense of competence are prone to self-doubts, anxiety arousal, threat appraisals of events and perceptions of coping deficiencies when confronted with difficult situations and demands (Bandura, 1989; Ozer & Bandura, 1990). Low sense of coping efficacy leaves people vulnerable to aversive experiences because they tend to worry, have weak task-specific competence expectancies, interpret physiological arousal



as indicative of anxiety, regard social feedback as evaluations of personal value, and feel more personally responsible for failure than for success. Given the fact that perceived sense of competence and depressive mood affect each other negatively and bi-directionally, the fourth manner of increasing people's beliefs consists of improving physical status, reducing stress, removing negative emotions and enhancing positive moods (Bandura, 1989, 1995). Yet, the speed of recuperation of perceived sense of competence after a person encounters impediments varies. As a result, some people recover their self-assurance quickly, whereas others lose trust in their capabilities. Thus a multitude of factors such as personal, social, and circumstantial influence how efficacy-relevant experiences are interpreted. Examples of such experiences include, people's prejudices of their abilities and perceived complexities of the task, the effort they expended, their emotional and physical status at the particular time and the situations under which they perform (Bandura, 1995).

In sum, there is evidence that perceived sense of competence can have diverse effects on psychological functioning and self regulation of cognitive processes (Ozer & Bandura, 1990). Consequently, individuals tend to avoid situations they believe go beyond their coping capabilities. On the other hand, they tend to promptly undertake activities that they judge themselves capable of handling. However, it can be argued that an optimistic perception of competence is essential not only because it raises aspirations and sustains motivation, but also because it contributes to psychological well-being and personal accomplishments through self-challenge, commitment and motivational involvement rather than through fearful self-protectiveness (Bandura, 1997).

### *2.1.3.2. The parental sense of competence*

The parental sense of competence is defined as the degree to which a parent feels competent and satisfied in handling the child's physiological and psycho-social needs and properly performs the parental role in the family (Binda & Grappa, 2000; Bogenschneider, Small, & Tsay, 1997; Herz & Gullone, 1999; Mash & Johnston, 1990; Reeve, 2005). Similarly, Coleman and Karraker (1997), state that in terms of the parental sense of competence-construct, perceived competence (efficacy), and contentment (satisfaction), are extremely intertwined with one another. As a result, it is impossible to attain a sense of competence without inherent satisfaction; and conversely, satisfaction is doubtful among activities for which little proficiency has been achieved.

According to Shaffer and Blatt (1990), feelings of competence emerge from the experience of mutually shared, reciprocal relationships and from an appreciation of the value of personal subjective experiences. Specifically, the development of the parents' sense of competence is related to a caring parent-child relationship in which parents are described as responsive, supportive, non punitive and non judgmental (Coleman, et al., 2002; Teti & Gelfand, 1991).

Parents' beliefs regarding their sense of competence should incorporate both the level of specific knowledge pertaining to the behaviours involved in child rearing and the degree of confidence in their ability to carry out the parental role. In other words, in order for parents to feel efficacious, they must possess the following: a) knowledge and understanding concerning their child's social, emotional and cognitive development b) awareness of appropriate child care responses, c) self-confidence in their own abilities to carry out such tasks, and d) the beliefs that their child will respond contingently (Barnard

& Martell, 1995; Coleman & Karraker, 1997; Schunk & Pajares, 2005). It is also important to note that the parents' beliefs and perceptions of their parenting practices tend to influence their motivation to change their parenting style (Ramey, 2002).

Furthermore, parents' appraisals and beliefs of their parenting performance in mastering the demands of rearing children are associated with parental feelings of satisfaction and perceptions of competence (Sabatelli & Waldron, 1995). A parent who has a sense of competence and satisfaction embraces responsible caregiving by protecting the child and, above all, assuring him/her of a secure base to support the psychological and social function of the child (Hoghughi, 2004; Lawson, 1993; Muzi, 2000; Rothbaum, Rosen, Ujiie, & Uchida, 2002). Accordingly, parents who feel more competent in their parental roles raise their children in ways that promote developmental opportunities for the children and minimize risks (Elder, Eccles, Ardel, & Lord, 1995; Fine & Kurdek, 1994; Taylor, Roberts, & Jacobson, 1997).

#### ***2.1.3.3. The diversity of factors influencing parental sense of competence***

The sense of competence construct is conceptualized as an essential component of an active system which is influenced by several factors and is modified following the changing demands of the task and individual developmental processes (Bandura, 1986, 1989; Bogenschneider, et al., 1997). With respect to the various factors that have been shown to influence parents' perceptions of competence, personal factors (i.e., parents' psychological functioning, parents' gender/roles, and parenting style), family relationship factors (i.e., marital relationship), social factors (i.e., poverty, low income, or unemployment, social integration, or lack of supportive social networks), and child

factors (i.e., child's temperament, age) represent the most significant (Anastopoulos, Guevremont, Shelton, & DuPaul, 1992; Bogenschneider, et al., 1997; Rubin & Mills, 1992; Webster-Stratton, 1990).

Among the personal factors, parents' psychological functioning such as depression problems, associated with high level of stress and anxiety can severely put at risk parents' well being and threaten their perceptions of competence (Baker & Heller, 1996; Coleman, et al., 2002). Several studies have indicated that maternal depression in particular, places mothers at increased risk for irritable interactions with their children, which in turn affect mothers' feelings of competence (Coleman, et al., 2002; Taylor, et al., 1997). Taylor and colleagues (1997), in their study on stressful events and parents' psychological well being show that mothers' depressive symptoms are also linked to mothers' negative perceptions of the maternal role and low maternal self-efficacy. Furthermore, mothers suffering from depression have been described as less sensitive and more punitive, negative, and rejecting toward their infants (Teti & Gelfand, 1991; Teti, Gelfand, Messinger, & Isabella, 1995).

In addition, parenting style may be considered an important factor for parents' enhancement of their sense of competence (Herz & Gullone, 1999; Coleman, et al., 2002). For example, "authoritative" parenting is documented as being the optimal parenting style with regard to child outcomes and parents' perceptions of competence (Herz & Gullone, 1999; Vrezh, 2006). Similarly, Vrezh (2006), has found a significant relationship between parents' sense of competence beliefs and parenting styles, such that endorsement of authoritative parenting techniques were positively correlated with a parental sense of competence, while endorsement of authoritarian parenting techniques

were negatively correlated with a parental sense of competence. Furthermore, various specific adaptive parenting skills have been found to be associated with a parental sense of competence. For instance, responsive, stimulating, non-punitive caretaking, and active maternal coping orientations have all been found to be related to a high maternal sense of competence.

Family relationship factors such as marital relationship should also be also mentioned. Happy and healthy marital relationships characterized by compliance and cooperation among partners contribute to positive parenting. It seems that good marriages support successful and competent parenting. In fact, a significant reciprocal relationship was found between marital satisfaction and parenting satisfaction for both mothers and fathers (Bogenschneider, et al., 1997; Rogers & White, 1998). Other studies have shown that, mothers who experience an affectionate and relatively conflict-free marital relationship feel competent in their parental roles (Haddock, Schindker-Zimmerman, & Lyness, 2002; Rubin & Mills, 1992).

With respect to socioeconomic factors such as poverty, low income or unemployment they can also produce enough stress to interfere with the parents' perception of competence in being responsive and sensitive to the child's needs (Black, Dubowitz, & Starr, 1999; Rogers & White, 1998; Taylor et al., 1997). For instance, low income parents face the grave psychological strains of trying to provide adequately for their children with limited monetary resources (Raver & Leadbeater, 1999). Studies have also revealed that the more that parents reported financial strain, the more harmfully they perceived their parental roles and responsibilities (Elder, et al., 1995).

Social support networks based on satisfactory interactions with support providers (i.e., health care professionals, social workers, friends) are positive related to parenting quality (Kurdek, 1998; Stewart, et al., 1995; Teti & Gelfand, 1991). Several investigators also found that the presence of a tightly knit social network was positively associated with parents' sense of competence in parenting (Gibson, 1995; Webster-Stratton, 1990). It is noteworthy to mention that social support is a significant determinant of individual differences in reaction to stress and a key resource for psychological well being (Cutrona, 1984; Stewart, et al. 1995). There are different kinds of support such as encouragement, advice, or tangible help that may come from various sources of support such as nuclear or extended family environment, friends or work associates (Cutrona, 1984). Benefits that may be gained from positive and constructive relationships with others lead to an increased sense of security, a reassurance of worth when the person's skills are acknowledged, and reliable alliance, when the person can count on others for assistance especially under difficult circumstances. It was demonstrated that social support help the parents' adjustment and their abilities to solve the daily problems with their child with chronic illness (Cutrona, 1984; Gibson, 1995). For instance, both tangible help such as money, housework or babysitting, and intangible aid such as advice and suggestions may help parents increase their feelings of competence. Knowledgeable or experienced others such as grand-parents, friends or even work associates may lessen parental self-blame by providing a different perspective in which problems are viewed less critical (Sourkes, 1995; Thomas, 1987). Social integration consists of having friends who share one's interests and concerns. In the case of parents who experience role strain in parenting their child with chronic illness, it may be beneficial to share and compare know-how with

other parents in similar situations (Gibson, 1995). This sharing will help parents feel that they are not unique in their problems and frustrations. Parents who received such social support reported higher levels of sense of competence in their parenting roles (Cutrona & Troutman, 1986).

Different factors related to the child's characteristics such as temperament, developmental age, developmental outcomes and child behaviour problems can also affect the parents' sense of competence (Anastopoulos et al., 1992; Bogenschneider, et al., 1997; Mash & Johnston, 1990; Sabatelli & Waldron, 1995). With respect to the child's temperament, research revealed that mothers' sense of competence as parents and their overall sense of well being were closely linked to the temperament of their children (Cutrona & Troutman, 1986; Teti & Gelfand, 1991). In particular, children with difficult temperament, or uncooperative and unresponsive children who return little positive feedback to their parents may undercut feelings and perception of parental competence (Bogenschneider, et al., 1997; Coleman, et al., 2002; Donovan & Leavitt, 1989). Thus, a parental low perception of competence leads to suboptimal performance of existing skills and a lack of persistence in problem-solving efforts (Bandura, 1982; Cutrona & Troutman, 1986). Similarly, parents of children with challenging or life-threatening conditions (i.e., chronic illness), are likely to feel that they are unable to recognize and end the distress, and unable to assert effective control and discipline over their children's behaviour and development (Barnard & Martell, 1995; Coleman et al., 2002; Hobbs, Perrin, & Ireys, 1985).

#### ***2.1.4. The Parental Roles and Gender Differences within Parenting***

Parenting roles are defined as the repetitive patterns of behaviour by which parents fulfill their child's and their family's needs, such as providing resources, nurturance, protection and support, assuring and promoting personal development and social interaction, as well as maintaining and managing the family system (Epstein, Ryan, Bishop, Miller, & Keitner, 2002; Gottfried, Gottfried, & Bathurst, 2002; Sclafani, 2004).

A mother's role, the so called "mothering", mainly consists of monitoring and being a responsive partner. Such a role develops in relation to the family system where other family members' functions are endorsed as well (Rothbaum, et al., 2002). Mothering is characterized by the long-term giving of one's time and interest in the form of enduring love, altruistic self, self-denial, and empathy. It is worthy to note that inside mothering there are some specific role functions that can describe a mother's role more explicitly. These functions embrace "managing", "caretaking", and "nurturing". The role of "managing" refers to a mother's capability to arrange all resources and synchronize the different activities within the family context in order to meet all family members' needs and expectations (Parke, 1995). Even though both mothers and fathers are equally able to perform this supervisory role, mothers are more likely to assume such a role (Barnard & Martell, 1995; Parke, 1995). While, the "caretaking" role consists of a mother's ability to provide care for both child and other family members, the "nurturing" role deals with providing an emotional support and love to the child and family and promote family relationships (Allen & Doherty, 2004; Emery & Tuer, 1993; Rothbaum, et al., 2002). The process of maternal role attainment definitely starts in pregnancy by getting good prenatal care and continues into the years following birth with a strong emotional attachment with



the child that promotes its survival and well being. Mothers' biological and social roles may intertwine over a lifetime of relationships with their own children, their grandchildren, and other people related to them through a variety of relationships (Bradley & Corwyn, 2004; Harkness & Super, 2002).

On the other hand, the paternal role, the so called "fathering", is less culturally scripted and determined than the maternal role, and few clear models for defining fatherhood exist (Arnold & O'Leary, 1997; Atkinson & Blackwelder, 1993; Pinkerton, 1997). However, with respect to the parental role, the existing literature provides an overview regarding the father's role attribution and evolution (Doherty, Kouneski, & Erickson, 1998; Labrell, 1996; Magill-Evans & Harrison, 2001; Palkovitz, 2002). Back in the nineteenth century, fathers' were attributed with the stereotyped role of provider, protector, yet emotionally uninvolved (Holden, 1997; Roach, Orsmond, & Barratt, 1999; Tamis-LeMonda, Shannon, Cabrera, & Lamb, 2004). The father was portrayed as a distant authority person, having little direct involvement with the children (Dienhart, 1998; Seward, 1994). At that time the father's role was defined mainly by his responsibility as a successful worker and breadwinner (Emery & Tuer, 1993; Riggs, 1997). These criteria were considered the most important for the appraisal of fathers as "efficient". Nevertheless, although the role of moral guidance and breadwinner remained a determinant characteristic of "good" fatherhood, attention focused on the father's function as a sex-role model in the early 1940's. Therefore, fathers emotionally invested in satisfying that role in various manners such as learning to control their temper and developing an active loving attitude, becoming more sensitive to children's desires, providing children with allowances or paying for highly structured education (Stearns,

1991). Around the mid-1970's, studies started to concentrate on the father's impact on his child's development by observing and appreciating his interactions with his children and relationships in the family.

Social definitions of fathering have changed from that of a "provider" to a "nurturer" and more "involved" person, whether as a husband or as a father (Carpenter, 2002; Griswold, 1997; Harris & Ryan, 2004; Lamb, 1997, 2000; Mackler, 2001; Yogman, Kindlon, & Earls, 1995). Nowadays, most fathers are doing substantially more in the home than their own fathers did, such as sharing household and childcare duties (Walsh, 2002, 2006). In addition, the father's involvement varies significantly and this variation appears to be mediated by the more general division of labor between husband and wife, their degree of emotional intimacy and associated living arrangements (Carpenter, 2002, Lamb & Lewis, 2004). Support is also growing for the belief that fathers contribute significantly to the child's gender-role identity, moral development and academic performance (De Luccie, 1996; Lamb & Tamis-LeMonda, 2004; Pinkerton, 1997). Fathers might bring different skills to their caregiving, which in turn provides particular benefits to their child's well being (Hawkins & Dollahite, 1997). Furthermore, recent work that has focused on father's interacting role as a play partner, suggests that fathers contribute in unique ways to the child's emotional, social and cognitive development (Gleason, 2005; Lindsey & Mize, 2000, 2001; Lindsey, Mize, & Pettit, 1997).

Nevertheless, focusing on family functions and dynamics, still today parental roles are influenced by gender stereotypes and parenting is often symbolized by the maternal affective function and paternal ethical function (Etaugh & Folger, 1998;

Scabini, 2000; Updegraff, McHale, Crouter, & Kupanoff, 2001). What is of particular importance for the parenting roles in terms of gender differences is the tendency to assume that gender differences are a product of the social roles typically held by women and men (French, 2002; Kerperlman & Schvanevelt, 1999; Riggs, 1997). Hence, societal prescriptions for men's and women's roles and the status they carry, influence the choices husbands and wives make about how they arrange their lives inside and outside the family (Cowan, Cowan, & Kerig, 1993).

In a traditional gender role division, women have been responsible for the well being of all family members and expected to tend to the needs of their spouse, children, and elders. On the other hand, men defined by job success, have been expected to be breadwinners and instrumental problem solvers, and have been constrained from intimate involvement in family life (Walsh, 2002, 2006). It seems that society still expects fathers to provide financially for their families. While mothers have the option of sacrificing financial well being for care giving, fathers who opt out of the breadwinning role meet with disapproval (Riggs, 1997). During the post-1970's demographic changes in the American family and the family roles for women were reassessed (Doherty, et al., 1998). Thus, for the first time, it has been emphasized that fathers in parallel with mothers, both could and should be nurturing parents actively involved in the day-to-day care of their children (Bornstein & Cheah, 2006; Doherty, et al., 1998; Harris & Ryan, 2004; Kozlowska & Hanney, 2002).

However, although both parents increasingly stress their need to share the family responsibilities, especially the childcare, the largest inconsistency between paternal and maternal caregiving tasks is the responsibility of ensuring that the child is appropriately

cared for at all times, rather than simply being available to “help out” when it is convenient (Bornstein & Cheah, 2006). So far, in two-parent families with employed mothers, the levels of paternal engagement and accessibility are both substantially higher than in families with unemployed mothers. As far as responsibility is concerned, even when both parents are employed, the amount of responsibility assumed by fathers appears negligible, whereas mothers still maintain the main responsibility for both child care and the household (Bonney, et al., 1999; Lamb, 1997; Roach, et al., 1999; Woznick & Goodheart, 2002).

Furthermore, when looking at parental gender differences in interacting with the child, many studies demonstrated that mothers and fathers engage in different styles of interaction. Basically, mother’s interactions with their children are dominated by caregiving activities with more instructions and directions than for fathers, whereas fathers are behaviorally defined as playmates and promoters of social activities (Bharadwaj, 1995; Laflamme, Pomerlau, & Malcuit, 2002; Lamb, 2000; Notaro & Volling, 1999; Stewart, 1999). Specifically, mothers more often than fathers maintain greater responsibility for promoting family relationships and providing their children with care, comfort and protection. On the other hand, fathers are more concerned than mothers with their children’s education and values (Emery & Tuer, 1993). The parenting literature has often compared father’s parent-child interactions with that of mothers, and concluded that fathers are less involved and lacking in their interacting behaviors (Dienhart, 1998; Knafl & Zoeller, 2000; Labrell, 1996; Wintersteen & Rasmussen, 1997). Previous studies on fathering revealed that paternal involvement in child care was influenced both by culturally defined norms and by individual beliefs (Bonney, et al., 1999; Doherty, et al.,

1998; Fagan, 2000). It is also evident that the kind of fatherhood role men follow might be affected by certain issues, such as socioeconomic position, marital role, cultural definitions, age cohort, timing, and perceptions of their own father. (Parke, 1995; Yogman, et al., 1995). In other words, fathers who reject the biological basis of gender differences, and perceive their caregiving skills as suitable, are more involved with their children. In addition, fathers interact differently with boys than girls showing more interest in sons mainly in nurturing manners and play activities (Fuligni & Brooks-Gunn, 2004; Thevenin, 1993; Yogman, et al., 1995).

With a particular regard to parental discipline, the literature presents imprecise outcomes concerning how and whether mothers and fathers differ in their discipline styles. For instance, though research findings suggest that mothers are more over reactive with their children than fathers, some other studies indicate the contrary (Arnold & O'Leary, 1997). Other studies support evidence that mothers also are those who note more child behaviour problems, and report a lower sense of competence as compared to fathers, whereas fathers reported a significantly lower and more situational parenting satisfaction than mothers (Bogenschneider, et al., 1997; Rogers & White, 1998; Webster-Stratton 1990).

It is interesting to note that some studies exploring patterns of family life have also looked into types of child care routines and household activities performed by men and women. So far, these studies suggest that the child care and household routines continue to reflect more traditional gender separation and specialization patterns on men and women (Dienhart, 1998). Some other studies on the participation of fathers in family labor confirmed that mothers usually do more household and child care duties than

fathers, interpreting fathers as uninvolved and unmotivated persons to perform their paternal role (Fagot, 1994; Hawkins & Dollahite, 1997; Woznick & Goodheart, 2002).

Emotional response and parental involvement in parenting reflect traditional gender-based parenting roles, as previously mentioned (Elliott-Brown & Barbarin, 1996). When we compare mothers' and fathers' emotional response to parenting, research studies suggest that mothers experience greater parental strain and are more expressive than fathers. The fact that fathers are often limited in expressing their feelings may be attributed to cultural barriers, social restrictions, economic factors and stereotypes concerning men's roles as a support to their spouses and as being strong and calm during hard times (Yogman, et al., 1995; Wintersteen & Rasmussen, 1997; Woznick & Goodheart, 2002). Paternal involvement with the child is influenced by forces both within and external to the family. An important influence on a father's involvement is the mother's feelings. The mother functions much as a gatekeeper, regulating the father's involvement with the child, and influences the father's relationship with his child even when he is not at home (Sclafani, 2004; Woznick & Goodheart, 2002; Tripp-Reimer & Wilson, 1991). Additionally, if a mother returns to full-time employment, a transitional period occurs during which she spends more time with the child in the evening, and this results in lower levels of father-child interactions. Moreover, the quality of marital relationship may affect fathers' involvement with their children (Parke, 1995). Fathers experience feelings of competition with their wives after the birth of a child. Stressful events outside the family may also have a major impact on father's involvement, for example a maternal illness, a child's premature birth or illness, a job insecurity or even a

loss of job associated with depression. These all may influence a father's psychological availability, involvement with a child and sense of competence (Parke, 1995).

However, with respect to gender differences within parenting, we need to remind ourselves that not all parents are the same, they approach parenting in the same way or they achieve the same results. Parents in different socioeconomic strata and cultures have different experiences, possess different beliefs, and behave in different ways with respect to their parenting (Bornstein & Cheah, 2006; Overton 2005; Rothbaum, et al., 2002; Stevenson-Hinde, 1998). A socio-cultural context may influence when and how parents exert their parental roles. As far as socio-cultural influences are concerned, both parents in literate societies were seen as playing a primary role as educators for their children regarding the values and the meaning systems of their culture. Differently, in societies such as sub-Saharan groups where husband and wife as a rule eat and sleep apart and have separate spheres of responsibility, fathers' involvement with the care of infants was found to be minimal or even culturally proscribed. On the other hand, in societies characterized by high intimacy and sharing of work roles, fathers and mothers share their childcare tasks (Harkness & Super, 2002).

In sum, it can be argued that "gender" is a fundamental organizing principle of people's lives, family relationship, and society (Haddock, et al., 2002). Traditional societal gender expectations for how men and women should behave continue to influence individuals' lives and shape their relations with family. Yet, these societal expectations are in transition and today individuals are striving to define themselves as well as their family roles and relationships. However, in North America, as far as maternal and paternal roles are concerned, the expectation nowadays is that parental

functions should not be divided between mother and father, but shared by both (Cigoli & Scabini, 2006; McCreary, 1990).

### ***2.1.5. The Parental Sense of Competence with an Ill Child***

In an attempt to understand the sense of competence construct in the parenting of a chronically ill child it is necessary to take into account the family system and its interactions. Parents not only have to deal with ever-changing challenges of their chronically ill child, but they also have to manage interdependent relationships within the family (i.e., parent-child dyad, parents-siblings and sibling-child interactions, and marital relationship) as well as within the extra familial social systems including educational, recreational, medical, and caregiving facilities (Anastopoulos, et al., 1992; Bandura, 1997; Sourkes, 1995).

Research suggests that the child's illness has an impact on both the family and also on the child (Gallo & Knafl, 1993; Hinds, et al., 1996; Masters, Cerreto, & Mendlowitz, 1983; Shepard & Mahon, 2002; Sourkes, 1995). Regarding family interactions in general, it has been demonstrated that families who have a child with chronic illness show less efficient and effective communication as shown by struggles to reach agreement (Gibson, 1995). The presence of a life-threatening illness, while linked most obviously to the ill child, creates changes in all the pre-existent interactions within the family. As a result, the parents' perceptions concerning their ability to effectively accomplish their parental roles affect their performance, which in turn, influence their interactions with the child (Ballenski & Cook, 1982; Coleman, et al., 2002; Lovejoy, et al., 1997; McBride, 1989; Shepard & Mahon, 2002).



According to Taylor and colleagues (1997), the most common change within family interactions is that the relationship between the chronically ill child and its parents, especially with the mother, becomes more privileged than was before. Such a relationship may also have an impact on the interactions between parents of a chronically ill child and healthy siblings. These interactions may appear as difficult and aversive which in turn may correlate with higher levels of parenting stress and alter parents' feelings of competence (Anastopoulos, et al., 1992; Gallo & Knafl, 1993; Gamble & Woulbroun, 1993).

Since parents and children make up a tight unit with one another, the well being of one is dependent on the well being of the other. Parents, especially mothers, who experience stressful events such as their child's life-threatening illness, are more likely to display less affection, acceptance, and monitoring and more likely to display aversive methods of control or discipline (Gamble & Woulbroun, 1993; Taylor, et al., 1997). In addition, the relationship between parental perception of efficacy and child behaviour problems is probably bidirectional. Thus, dealing with difficult child behaviours may make parents feel less efficacious in the parenting role and less effective parenting may also engender more problematic child behaviour (Lovejoy, et al., 1997). Similarly, parents of unusually demanding children (i.e., chronically ill or children with hyperactivity) show lower levels of parenting sense of competence than parents of less difficult children (Coleman, et al., 2002; Fischer, 1990; Pisterman, et al., 1992). Additionally, Mash and Johnston (1990), found that both mothers and fathers of children with hyperactivity have reported significantly lower levels of parenting sense of competence than parents of children without behaviours problems. An important issue

within the parent-child relationship that should be considered which in turn may affect parents' sense of competence is the parental attitude toward the sick child (Masters, et al., 1983). Parents may change their attitudes towards the chronically ill child; some parents become more loving and indulgent; some others minimize their discipline and rules; others may reject, criticize, or even neglect the child (Gallo & Knaff, 1993; Gamble & Woulbroun, 1993). However, it can be argued that positive perception of competence breeds a recognition of personal potential for accomplishing goals and success in performing existing roles or undertaking new ones, especially in the context of a childhood chronic illness (Fitzgerald Miller, 1992).

With respect to the marital relationship, although some investigators have found that the presence of a child's chronic illness has little or no impact on divorce rates, some others have shown a somewhat reduced incidence of divorce, despite the fact that the experienced stress had a cohesive effect on the solidarity of the marriage (Eiser, 1990; Hayes, 2001; Shepard & Mahon, 2002). While there is no evidence of a higher than average divorce rate in families with a child with chronic illness, it is obvious that there is considerable strain on the marital relationship. Parental couples often have less time to spend together in order to satisfy their own personal needs and very little opportunity to relax away from the home (Eiser, 1990).

Specific changes in family members with respect to their social interactions can also be noted. Not only are social isolation, restricted social network or even withdrawal very typical to the families who are parenting a chronically ill child, but also relatives or family's friends may eventually withdraw as well (Fitzgerald Miller, 1992). Certain valued social activities may be eliminated or restricted, due to increased difficulty to

manage time and energy or to the parents' fear and stress to expose their ill child too often (Thomas, 1987). As a result this bidirectional social isolation may contribute to further lowering parents' perceptions of competence because of the absence or lacking feedback, advices or support from the others (Fitzgerald Miller 1992). It is noteworthy to mention that positive relationships with significant others such as members of extended family (grand-parents, uncles, cousins), friends or even work associates who provide support may exert a protective function against depression and stress by enabling parents to master the challenging situation and perceive themselves as more effective in accomplishing their parental roles (Cutrona & Troutman, 1986; Donovan, et al., 1990; Sourkes, 1995).

Family relationships with different professionals (i.e., health care providers, doctors, nurses and school teachers) who also take care of the chronically ill child should also be considered with respect to the influence that these relationships may exert in fostering or lowering parents' sense of competence (Turner, et al., 1990). Health professionals, as the experts of the domain of illness, can provide support to the parents, such as an accurate information about the child's health status, plans for care and future projections (Gibson, 1995). Although parents need such an approach from the different professionals in order to better cope with their child's illness, they also want respect and acknowledgement for their assessments as well as opinions and suggestions on their child's health issues. Parents want their abilities and expertise to be recognized. Therefore, a sense of parenting satisfaction and competence can derive when there is a mutual exchange and respect between professionals and parents (Derbyshire, 1994; Gibson, 1995; Thomas, 1987, 1996). On the contrary, professionals' lack of

acknowledgment of parents' abilities and their disregard of parents' perspectives may lead to minimize the parents' sense of competence in performing their roles (Derbyshire, 1994).

In sum, it can be assumed that parents of children with chronic illness are faced with additional and challenging demands compared to those experienced by parents of healthy children (Rodrigue, et al., 1994). As a result, parental sense of competence may be further compromised when they try to face challenges and uncertainty in rearing a special needs child (Bandura, 1997; Ohan, et al., 2000). Therefore, in parenting a child with chronic illness who manifests different physical, psychological and behavioural problems compared to a healthy one, it is important to recognize that the parents' emotions and cognitions play an essential role in parent-child interactions (Ohan, et al., 2000).

#### ***2.1.6. Summary***

Parental perception of competence plays a key role in adaptation to parenthood and positive parenting practices and may predict quality of child and marital relationship (De Luccie, 1996; Kurdek, 1998; Raver & Leadbeater, 1999). Furthermore, parents who possess a high sense of competence are active in promoting and encouraging their children's competencies both inside and outside the family environment. As reported by Coleman and Karraker (1997), effective parents are able, even in the context of many stressors, to struggle with threatening situations and to simultaneously provide constructive experiences for their children. While parents try to acquire sufficient knowledge and skills in order to be able to guide their children adequately through the

various phases of their development, in some cases, it can be a very difficult period for parents who are unprepared to carry on the parenting role. Disadvantaged conditions such as being a single parent family or facing financial strains also weaken parents' sense of efficacy leading to feelings of hopelessness (Bandura, 1995).

It can be assumed that there is a relation between parents' perception of competence and their behaviour in dealing with the uncertainty. We believe that Sorrentino's Uncertainty Orientation theory regarding individual behaviour towards uncertain circumstances is consistent with the Bandura's (1997) self-efficacy theory, which also states that perception of competence is related to an individual's selected coping behaviour.

To conclude, in this chapter we provided a review of literature exploring two major concepts: the uncertainty and the sense of parenting competence. An explanation of the concept of the uncertainty within two theoretical frameworks was given followed by the description of coping with uncertainty in illness. Parents' sense of competence in parenting, their parental roles and gender differences with emphasis on fatherhood was also outlined. Furthermore, different factors influencing parental perception of competence were included. Finally, a description of parental sense of competence with a child with chronic illness was presented. This study is focused on parents' perception of competence and uncertainty while parenting their child with leukemia. In the following chapter we describe the methodology used to understand parents of children diagnosed with a chronic illness such a leukemia.

**CHAPTER III**

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## **3.1. Methodology**

### ***3.1.1. Chapter Overview***

The present research is an exploratory descriptive case study of parents having a child with leukemia combining quantitative descriptive analysis and qualitative approaches for the data collection and analysis. The goal of this chapter is to describe the methodology that informed the study. The chapter begins with a description of the socio-demographic information of the participants. Next, I offer a description of the instruments used in terms of their characteristics and pertinence for the purpose of the study. Then, the data collection procedure is outlined. The chapter concludes with a description of the data analysis procedures and issues of validity.

### ***3.1.2. Description of the Sample***

A total of 18 parental couples with children with leukemia in the range of 4 to 12 years of age were selected from the “Leucan” Childhood Cancer Association located in the town of Montreal. “Leucan” is a non-profit organization that was founded in 1978. Its mission is to promote greater well-being and healing among children with cancer and to provide support for their families. In addition to its head office in Montreal, “Leucan” has eight regional development committees and 5,000 members across Quebec and it is present in the four main paediatric oncology centers in Quebec: St. Justine’s Hospital, the Montreal Children’s Hospital, the Centre Mère-Enfant du CHUQ in Quebec city, and the CHUS in Sherbrooke. Each year, it follows the cases of more than 1,600 children with cancer. “Leucan” has developed a comprehensive range of programs and services to

better meet the needs of families such as: information and referrals, financial assistance, emotional support, massage therapy, social and recreational activities and school awareness. “Leucan” is also recognized as a referral centre for similar institutions in both the United States and Europe.

As soon as the approbation to conduct the study from the University Committee on Human Subjects was obtained, parents were solicited from the “Leucan” Childhood Cancer Association of Montreal. At the beginning, a meeting with the coordinator for the “Leucan” association and the researcher was arranged in order to discuss the purpose of the study as well as its possible implications for the development of a parental educational program in the future. Once the center agreed to participate in the study they helped with the initial contact of possible participants for the study. Due to ethical reasons of confidentiality of parents’ demographic information a professional from the “Leucan” association took charge of the preliminary selection of participants. The professional contacted different parental couples with children with leukemia that met the following criteria: First, a couple’s participation was required. Therefore, only couples where both parents agreed to participate were accepted. Second, only couples with children who were in the remission phase of the illness were selected. This was important in order to avoid the bias of the devastating impact of stress and anxiety on parental coping strategies and perceptions of competence following initial cancer diagnosis. Third, all participants had to be able to read and speak English in order to effectively provide answers to the Parenting Sense of Competence Scale (PSOC) and the Uncertainty Orientation measures. Yet some parents did conduct the interview in French rather than English since they found it easier to express themselves in that language.



Based on such criteria, a total of 32 couples were contacted among which 25 expressed an interest to participate and 18 couples met the selection criteria of the research, and hence, were contacted by the researcher. The socio-demographic characteristics of the participating couples are presented in Table 1. A total of 18 sets of parents between the ages of 25-49 years participated. Among the participating parents, 10 couples are Canadians, 2 couples mixed from Canada and other countries and 6 couples are immigrant from Eastern and Western Europe, Africa and the Americas. As will be discussed later, however, the differences in ethnic backgrounds and immigrant status were not considered in the interpretation of the data as variables due to small sample size and vast diversity in terms of countries of origin.

All participants are well-educated having completed their secondary education and obtained a post-secondary degree or diploma. Among the parents, 3 mothers and 5 fathers attended undergraduate studies and 1 father had a postgraduate degree. The parents' occupation indicates that the majority are professionals (11 mothers and 14 fathers), whereas 1 mother and 3 fathers are running their own business. As revealed in Table 1 most parents are of middle socioeconomic status and are employed: 12 mothers and 17 fathers are working. At the time of the study, 3 mothers were unemployed and 1 father was on welfare.

Table 1 The Socio-Demographic Characteristics of the Parents

Family code	Parents' ethnicity	Parents' age	Parents' education	Parents' occupation	Parents' occupational status	Parents' Annual income	Child age	Child clinical situation (remission)	Siblings
1	Canada (m-f)	40-45	Diploma (m) Undergraduate (f)	professional (m) unemployed (f)	employed (m-f)	>180.000	3 yrs	1 <sup>st</sup> yr	5
2	Canada	45-49	Undergraduate Diploma	unemployed professional	unemployed employed	40.000-59.000	7 yrs	2 <sup>nd</sup> yr	2
3	Canada France	40-45	Post-secondary Diploma	professionals	employed	0-39.000	7 yrs	6 months	1
4	Peru	45-49	Diploma	professionals	employed	40.000-59.000	9 yrs	2 <sup>nd</sup> yr	3
5	Haiti	40-45	Diploma Undergraduate	professionals	employed	60.000-79.000	3 yrs	1 yr	3
6	Canada	40-45	Diploma Post-secondary	manager manager	employed	120.000-139.000	11 yrs	18 months	1
7	Canada	40-45	Diploma/ High school	labourer professional	unemployed employed	140.000-159.000	10 yrs	2 <sup>nd</sup> yr	2
8	Canada	35-39	Undergraduate	professionals	employed	140.00-159.000	11 yrs	2 <sup>nd</sup> yr	1
9	Tunisia	40-49	Diploma	professionals	employed	0-39.000	8 yrs	1 <sup>st</sup> yr	1
10	Lebanon	35-39	N.A./Diploma	N.A/ manager	N.A./employed	40.000-59.000	3 yrs	1 <sup>st</sup> yr	1
11	Canada	40-45	Diploma/N.A	N.A/ professional	N.A./employed	60.000-79.000	8 yrs	2 <sup>nd</sup> yr	1
12	Canada	35-39	Undergraduate Postgraduate	professionals	employed	120.000-139.000	5yrs	2nd	1
13	Senegal	25-34	High school Undergraduate	professionals	unemployed. employed	40.000-59.000	1yrs	2 months	0
14	Canada	39-45	Post-secondary Undergraduate	clerical professional	employed	100.000-119.000	6yrs	1 <sup>st</sup> yr	1
15	Nederland Canada	35-39	Diploma	professionals	employed	N.A	11 yrs	8 months	2
16	Canada	35-39	Post-secondary	professional/N.A	employed	60.000-79.000	5 yrs	16 months	2
17	Romania	40-45	N.A./ Undergraduate	N.A/ professional	N.A /welfare	N.A	6 yrs	9 months	1
18	Canada	35-39	Diploma	professionals	employed	60.000-79.000	3 yrs	4 months	2

As Table 1 shows, children with leukemia ranged between the ages of 3 and 11 years, with the exception of one child who was only one year old. There are two reasons for selecting preschool and school age children with leukemia. First leukemia is one of the most frequent malignancies in children of this age group (Pui, 1997; Pui & Evans, 1998). Second, adolescents with leukemia typically experience issues different than do preschool and school age children in terms of their relationship with their parents, siblings and also in terms of how they deal with the illness itself. The focus on preschool and school age children makes evident one attempt in trying to minimize some variability in the data set.

In terms of Acute Lymphoblastic Leukemia, remission means a disappearance of all signs and symptoms of cancer while cancer may still be in the body (National Cancer Institute of Canada, 2005). During the remission phase that lasts two years and in some cases three, all children receive an intensive medical therapy once or twice a week, always in a hospital setting, that includes a drug combination with a variety of very disturbing side-effects (Pui & Evans, 1998; Veerman, Hahlen, & Kamps, 1996). Hence, the remission phase may still be challenging to both the child and its family.

### ***3.1.3. Data collection***

Data entailed semi-structured interviews and various questionnaires which will be presented in the following section. All raw data collected from the interviews and the questionnaires were handled directly by the researcher, to assure complete anonymity and confidentiality of the participants. The interview data were gathered with the help of

recording equipment. Names, addresses, phone numbers and any personal information of the participants were kept confidential.

#### ***3.1.3.1. Description of instruments***

Given the dual purpose of this study to describe the parent's perceptions of uncertainty along with the parental perceptions of competence, the following four instruments were adopted:

##### 1) The socio-demographic questionnaire

The socio-demographic questionnaire, presented in Appendix II, was used to gather information about the participants' ethnicity, age, level of education, occupation, occupational status, household annual income and number of children. This questionnaire was completed by each parent individually.

##### 2) The interview

A semi-structured interview was developed to explore parents' orientation towards uncertainty and their perceptions of competence in parenting their children with leukemia under life-threatening circumstances. The semi-structured interview makes possible to capture how a person thinks about a particular theme. While questions developed ahead of time give the interview structure and ensures that all parents may be asked the same questions, its semi-structured nature makes true dialogue possible also in that the researcher is receptive to it and tries to conduct the interview as a conversation (Fontana & Frey, 2000). The process of a semi-structured interview involves the preparation of an interview guide that lists a predetermined set of questions that are to be explored during an interview by eliciting specific answers on the part of the respondents.

Such a guide serves as a framework for the interview and ensures that basically the same information is obtained from the participants (Marshall & Rossman, 1995). The advantage of the interview guide in the semi-structured interview is that it makes interviewing more systematic and comprehensive by setting boundaries within which answers have to be provided. This allows answers to remain focused on the issues to be taken up in the interview. Moreover, semi-structured interviews are often used to obtain information that can later be compared and contrasted (Fraenkel & Wallen, 1993). In the semi-structured interviewing open-ended questions are designed to provide detail and meaning at a very personal level and have as an obvious advantage the freedom of the respondent to express an opinion as he/she wishes. Open-ended questions are intended to encourage a full, meaningful answer using the subject's own knowledge and/or feelings (Jones, 1985). In the present study, given the very stressful and challenging circumstances that parents experience, the interview questions were formulated in a certain way that would elicit pertinent and meaningful responses without intimidating the participants from expressing themselves (Goicoechea, 2006). The interview protocol was subjected to pilot testing before use (Krathwohl, 1993). The purpose of the pilot testing procedure was to ensure that all the data required for the study would be obtained from the questions asked. The questions had to provide data on how parents experienced the pleasures and challenges of parenting in general which is part of their sense of competence, and how the parenting might differ with a chronically ill child. Questions were also created to assess the parents' feelings of uncertainty and their ways of coping with these feelings were also explored by questions pertaining to the parents' perception of the future.

A total of 9 open-ended questions were formulated making up the four parts of the interview: 1) description of parenting 2) perception of role as a mother/father with a child with chronic illness in the family 3) perceptions and coping with uncertainty and 4) perceptions of the future. The first part of the interview included two descriptive questions (i.e., “would you like to describe to me some of the joys, pleasures of parenting?” and “could you tell me about some of the challenges of the parenting?”), with the aim to assess parents’ explanations about their pleasures and challenges of parenting in general. The interview began with these descriptive questions to encourage parents to talk about their daily experiences as parents. The descriptive questions were also inspired by the themes of the Parenting Sense of Competence questionnaire and aimed to elicit a large sample of expressions that would indirectly reveal parents’ feelings of satisfaction (i.e., talking about pleasures) and efficacy (i.e., talking about challenges) in performing their parental roles. Given that the concept of sense of competence, as previously explained, includes both the satisfaction component – feeling good - and the efficacy component – reflecting competence - (Bandura, 1997; Coleman & Karraker, 1997), the creation of the above descriptive interview questions appeared appropriate in eliciting such feelings.

In the second part of the interview, parents were invited to talk specifically about parenting their child with leukemia and the perceptions they have with respect to their parental roles in this new and different situation. Once again, two descriptive questions or so called “grand tour” questions were asked. According to Spradley (1979), “grand tour” questions lead to rich descriptions, including many aspects of experiences such as space, time, events, people or activities. In other words, descriptive grand tour questions such as

“Could you describe to me your parenting now that you have an ill child?”, and the expanding descriptive question “Is there something particularly challenging to you as a mother/father of an ill child?” were formulated in order to elicit a large sample of utterances about the many aspects of the parents’ daily experiences. Although these questions may appear rather direct and have the potential to be upsetting for the participants, trust could be established initially through the other questions between myself as a researcher and the parents, making these more pointed questions non-threatening. Finally, a direct question regarding parents’ perception of their role was also asked with the purpose of gathering further explanations of that experience and to reveal feelings of satisfaction and efficacy in parenting under life-threatening circumstances. It is also noteworthy to mention that the order of the questions in the second part was not rigid but flexible and shaped by the participant’s comfort and ability to answer.

The third part of the interview addressed parents’ encountered uncertainties and their strategies of coping with such uncertainty. Inspired by the literature, to ask parents a question about their experienced uncertainties and their ways to cope with such an ambiguity appeared particularly pertinent and promising. As previously mentioned, supporting evidence states that feelings of uncertainty lead to the adoption of different strategies of coping which in turn reveal the individual’s orientation towards uncertainty as well as his/her preferences to resolve uncertainty or to maintain clarity (Sorrentino & Roney, 1986, 1999, 2000; Sorrentino et al., 1995). I was also very interested to discover what kinds of feelings of uncertainty parents may have experienced thinking that such will probably bring to light an association between feelings of uncertainty and coping processes in relation to their perceptions of satisfaction and/or efficacy as parents. These

kinds of questions helped reveal additional qualitative data regarding parents' preferences towards uncertainty orientation.

Finally, the fourth part of the interview focused on parents' perceptions of the future in terms of hope, fear and worries. This question was formulated with the intention to elucidate parents' visions about their life in the future and also to gather further insights into their ways of dealing with uncertainty. They were also explicitly requested to talk about what advice they would give to other parents that would help them cope better. The total of 9 open-ended questions that were formulated to cover the aforementioned themes are presented in Appendix III. A transcript of a parent's interview in French is also provided in Appendix VI. Table 2 shows the theoretical concepts at the base of the study and the related interview questions.



Table 2 A Presentation of the Theoretical Concepts of Study with the Interview Questions

Theoretical concepts of study	Interview questions
Sense of Competence	<p>Q 1. Would you like to describe to me some of the joys, pleasures of parenting?</p> <p>Q 2. Could you talk to me about some of the challenges of parenting?</p> <p>Q 3. Could you describe to me your parenting now that you have a child with leukemia?</p> <p>Q 4. How do you perceive your role as a mother/father in this particular situation?</p>
Perception of Uncertainty	<p>Q 6. Are there some issues with respect to parenting, now with an ill child, that remain ambiguous or confusing to you?</p> <p>Q 7 When you feel ambiguity or confusion, how do you cope with such feelings?</p> <p>Q 8. Would you like to talk to me about your life in the future?</p> <p>Q9. If you think of all that happened to you as a parent since your child was diagnosed, what kind of support and advise would be the most helpful for other parents who find themselves in your situation?</p>

### 3) The Parenting Sense of Competence Scale (PSOC)

The PSOC scale is a 16-item Likert-type questionnaire with 7 items measuring efficacy and 9 items satisfaction (Appendix IV; Gibaud-Wallston & Wandersman, 2001; Johnston & Mash, 1989). Answers are rated on a 6-point scale, ranging from 1 (*strongly agree*) to 6 (*strongly disagree*). A minimum of 16 score reflects very low efficacy and satisfaction and a maximum of 96 score reflects a very high efficacy and satisfaction. The PSOC scale was used for this research study in its original form to assess parents' perceived satisfaction and efficacy with respect to parenting a child with a chronic illness. All items on the Satisfaction scale are reverse-scored (i.e., 2, 3, 4, 5, 8, 9, 12, 14 and 16) so that, for all items, higher scores indicate greater parenting self-esteem. The numeric values from each answer of both efficacy and satisfaction subscales were summed and

means and standard deviations were calculated. This questionnaire is one of the most frequently employed and well-researched measure of perceived parenting abilities, competency, and self-esteem. It has proved useful in normal and in clinical samples (Baker & Heler, 1996; Harvey, 1998; Hoza, et al., 2000; Johnston, 1996; Rogers & White, 1998). This instrument was developed originally to measure maternal confidence, skills of mothers, and their value of being a good mother (Gibaud-Wallston & Wandersman, 2001). Subsequently, the Parenting Sense of Competence Scale was modified and adapted to assess self-esteem of both mothers' and fathers' parenting preschool and school-age children, entailing two dimensions: the perceived efficacy as a parent and the satisfaction derived from parenting (Johnston & Mash, 1989). Efficacy, an instrumental dimension of parental sense of competence reflects competence, problem-solving ability, and effectiveness in the parenting role. Satisfaction, an affective dimension of the parenting sense of competence, pertains to measure frustrations, culpability, anxiety, and motivation. The PSOC scores are not related to social desirability and did not vary as a function of child age or sex (Johnston & Mash, 1989). Johnston and Mash (1989) have reported internal consistencies of .79 for the Total Score, an alpha of .75 for the Satisfaction scale, and an alpha of .76 for the Efficacy scale. Also, Ohan, Leung, and Johnston (2000) in their study of 110 mothers and 110 fathers of 5-to 12-year-old boys and girls have reported internal consistencies. For mothers, the internal consistency of both the Efficacy and Satisfaction scales was .80. For fathers, the internal consistency of the Efficacy scale was .77 and the consistency of the Satisfaction scale was .80. The authors addressed the validity of the PSOC scale by calculating partial

correlations between Efficacy and Satisfaction scores and other measures of family functioning.

#### 4) The Uncertainty Orientation Measures

The Uncertainty Orientation measures (Sorrentino, et al., 1992; Sorrentino, Hanna, & Brouwers, 2001), were used to assess a person's orientation toward uncertainty. Originally, Uncertainty Orientation was designed to examine individual differences in cognition related to achievement behaviour, but it is now used to measure many related areas of general psychology. The Uncertainty Orientation measures predicts differences about informational items (i.e., uncertainty about an outcome or one's ability). These measures are typically administered to subjects in mass testing sessions (Huber, Sorrentino, Davidson, Epplier & Roth 1992; Sorrentino & Roney, 1986) and consist of two independent instruments: 1) a projective measure which reflects a person's orientation towards resolving uncertainty, and 2) a personal opinion questionnaire which reflects an individual's orientation toward maintaining certainty.

a) The projective measure. The projective measure of Need (n) for Uncertainty (Appendix V; Frederick & Sorrentino, 1977), relies solidly in its conceptualization on Kagan's notions concerning modes of uncertainty resolution (Kagan, 1972, in Sorrentino, et al., 2001). Such a measure is administered first and contains four sentences that present certain situations to be elaborated according to the following prompts:

- 1) "Two people are working in a laboratory on a piece of equipment";
- 2) "A person is sitting, wondering about what may happen";

- 3) “A young person is standing: Some kind of operation can be seen in the background”; and
- 4) “A person is thinking: An image of a crossroads is in the person’s mind.

Each one of those sentences is presented along with four identical prompts (Appendix V) that help subjects write a story within a period of four minutes for each situation. This projective measure for nUncertainty utilizes a similar scoring system and procedure to those developed for nAchievement, nPower, and nAffiliation (Sorrentino, et al., 1992; Sorrentino, et al., 2001). Written stories are coded for evidence of interest in resolving uncertainty given the unknown conflicting ideas, or information that conflicts with existing ideas. Stories are scored on the basis of the richness of the evidence for concern about uncertainty resolution (Sorrentino, et al., 1992). The higher the score, the more uncertainty-oriented the person is. Although the nUncertainty scoring manual yields high interrater reliability (all of the scorers yield above .90 with the scoring manual and other expert scorers) the internal consistency ( $\alpha = .12$ ) and test-retest reliability are low ( $r = .35$ ).

b) The 21-item acquiescence-free authoritarian scale (Cherry & Byrne, 1977), is a personal opinion questionnaire which covers many and opposite points of view. This questionnaire is answered on a 6-point scale from +3 (*strongly agree*) to -3 (*strongly disagree*) measuring how a person feels in each case. The questionnaire is utilized in order to infer participants’ orientation towards maintaining certainty. Authoritarianism is used for this component because it involves a concern with familiar and predictable events. Therefore, a preference for the known and aversion for the unknown and unfamiliar, presents a sign of certainty orientation. Thus it is used to make up half of the

total uncertainty orientation measure (Sorrentino, et al., 1992; Sorrentino et al., 2001). The authoritarianism measure has high test-retest reliability as well as high internal consistency (all above .86). Research studies have demonstrated repeatedly that either component alone is not sufficient to evaluate an individual's uncertainty orientation. Therefore, the resultant measure of uncertainty orientation is calculated by transforming both measures to Z-scores and afterwards by subtracting the authoritarianism Z-score from nUncertainty Z-score (Sorrentino, et al., 1992; Sorrentino, et al., 2001;). The range of scores is then subject to a tertile split. It has been recommended that analyses of the Uncertainty Orientation measures should be performed by using only the upper and lower thirds of the resultant measure (i.e., uncertainty-oriented persons equal the upper third, certainty-oriented persons equal the lower third). Median splits and correlational analyses are not recommended due to the fact that subjects in the middle third tend to behave inconsistently (Sorrentino, et al., 1992).

To summarize, the resultant measure of Uncertainty Orientation has already been shown to have predictive as well as concurrent validity. First, its predictive validity is demonstrated by two laboratory studies and a field experiment (Sorrentino & Hewitt, 1984). In the latter, grades in an introductory psychology course supported a priori predictions based on the Uncertainty Orientation measures. Concurrent validity was established by the fact that the nUncertainty measure produced mirror image results with its counterpart from the resultant measure, authoritarianism. Second, the nUncertainty measure follows traditional means of validating the projective measures of nAchievement, nPower, and nAffiliation recommended by Atkinson and his colleagues (Atkinson, 1958, in Sorrentino & Hewitt, 1984). Furthermore, The validity of the

Uncertainty Orientation measures has been demonstrated in prior studies such as: individual differences in uncertainty orientation and cooperative learning (Huber, et al., 1992), individual differences in risk-taking regarding uncertainty orientation and achievement-related motives (Sorrentino, et al., 1992) individual differences in uncertainty orientation and trust in close relationships (Sorrentino, et al., 1995). It is noteworthy to mention that the Uncertainty Orientation measures presented here are used for large adult populations (academic or not academic). Children's versions also exist for children in grades 3-5 and 6-8 (Sorrentino, et al., 1992). In the present research study the Uncertainty Orientation measures are used in their original form to assess a small group of parents' personal orientation toward uncertainty under a life-threatening context.

#### ***3.1.3.2. Procedure***

The researcher made initial contact with the parents by telephone and described the study and answered immediate questions. After receiving the parents' verbal agreement for participation (Appendix I), an appointment was scheduled in the parents' home for the conduct of the study. Follow-up phone calls were also made with those couples who wished to think about their decision to participate or needed to verify scheduling availability of their partner. During the meeting, the parents were asked to first complete the socio-demographic questionnaire which lasted about 10 minutes. Next, the semi-structured, face-to-face, interview was carried out at the parents' home with one parent while the other completed the Parenting Sense of Competence Scale (PSOC). I began each interview with an informal conversation that helped to establish rapport with the participants and gain their trust, both important elements for the success of the interviews (Fontana & Frey, 2000; Krathwohl, 1993; Spradley, 1979). Each parent was

interviewed individually and without the presence of his/her partner, in order to avoid partners' influence and to provide all parents with the opportunity to express themselves freely. The interview session lasted approximately 30 to 40 minutes. When both parents finished their interview sessions along with the Parenting Sense of Competence Scale, they were asked to complete the Uncertainty Orientation measures. Parents were allowed to complete the Uncertainty Orientation measures at the same time and place but without talking to each other. The projective measure was administered first. Both parents were timed by the researcher and had a total of 17 minutes and 30 seconds to complete this measure (i.e., 20 seconds to read each sentence and 4 minutes to write out a story). Timing was very important for the completion given the purpose to write down as quickly as possible the story that came to mind. No additional time was given even if the parents did not complete their stories. Once they accomplished the projective measure, parents were asked to complete the 21-item acquiescence-free authoritarian scale, a personal opinion questionnaire. Since the latter was not timed by the researcher, parents were invited to take their time, if necessary, to properly complete it. The duration of the whole experimentation for each couple lasted from two to three hours approximately. No additional appointments with the parents were necessary. Hence, the interview sessions with the 18 couples were conducted over a period of five months.

Considering the parents' situations at home and how they often deal with other family issues such as taking care of the siblings or doing other activities, it was not always possible to respect a precise order of testing which starts with socio-demographic questionnaires, followed by the interview and ending with the Parenting Sense of Competence scale and the Uncertainty Orientation measures. Sometimes the pre-

established testing order was not respected to avoid making parents feel overwhelmed by such a study

### ***3.1.4. Data analysis***

#### ***3.1.4.1. Analysis of interviews***

All the interviews were transcribed verbatim - the essential raw data for qualitative analysis - by the researcher within a period of eight weeks following the data collection phase. Transcribing offers another point of transition between data collection and analysis as part of data management, and hence, doing the transcription provided an opportunity to get fully immersed in the data and gather further insight and understanding (Patton, 1990, 2002). Note that the interviews were transcribed in a way that stayed as close as possible to their meaning, and no grammatical or syntactical corrections to the participants' sentence structures were made (Patton, 1990). Transcription also leads into a preliminary interpretation of the data that consists of "asking questions", "formulating hypothesis" and "searching for meaning" (Patton, 1990; 2002). As soon as all the transcriptions were finished, I verified that they were all accurate.

Prior to the content analysis, interview data needed to be organized; therefore three complete copies of all of the data were created, one master copy for safekeeping and two copies for different kinds of analysis. Once copies were made of the data, I proceeded with the content analysis. Spradley (1979), stated that the content analysis involves a way of thinking and it has to be done with respect to the original problem and the specific research questions. Furthermore, both Patton (1990), and Creswell (1994), affirmed that the analysis of qualitative data is an eclectic and very creative



process that consists of identifying, coding, and categorizing the primary patterns of the data. The process of content analysis for this study implies an inductive qualitative approach (Lincoln & Guba, 1985; Patton, 2002). Within an inductive analysis I looked at the data for undiscovered patterns and emergent understanding (i.e., creation of new categories) with the purpose to report how people construe their world of experience from the way they talk about it (Bourgeois & Piret, 2006; Wiersma & Jurs, 2005).

Two theoretical concepts were examined in this study; the sense of competence and the perception of uncertainty and coping. For each theoretical concept the related four interview questions were taken into consideration and analyzed inductively (see Table 2). As Lincoln and Guba (1985) suggest, an inductive analysis implies two processes, the “unitizing” and the “categorizing”. Through “unitizing” the raw data from the participants’ answers to the questions were systematically transformed and collected into units that would serve as the basis for defining categories. These units were simple sentences or extended paragraphs that stand by themselves and were comprehensive without any additional information. I started to re-read and re-examine all the interview questions to one particular question, and tried to understand the underlying meaning and by identifying its units. Then by “categorizing”, the previously unitized data were organized into categories or themes that would provide descriptive information about the shared meanings among these units.

I proceeded with Spradley’s domain analysis. According to Spradley (1979), a domain is defined as any symbolic category that includes other categories. In the present study, the following domains or themes were explored: “pleasures of parenting”, “challenges of parenting”, “sense of competence”, “uncertainty”, “coping”, “perception

of the future”, and “parental advice”. The first element in the structure of a domain is a *cover term* which is the name for a category of knowledge (Spradley, 1979). Each domain includes one or more terms that are linked together through universal semantic relationships such as “strict inclusion” (is a kind of), and “means-end” (is a way to do). For example, “pleasures of parenting” is a cover term for a larger category of knowledge that includes other kinds (categories) of pleasures or sub-categories such as “sharing love”, “enjoyment child’s accomplishments/development”, “providing education/values”, and “spend quality time with the child”. Specifically, “sharing love” (included term/category) forms a kind of semantic relationship with “pleasures of parenting” (cover term/domain). Similarly, the domain of “coping” for example, includes several sub-terms or categories such as “living day by day”, “seeking information/understanding”, “talking to others” that are linked semantically with ways of dealing with uncertainty. By proceeding with the analysis in such a manner, I ensure that there remained a semantic relationship between the cover term or category and sub-category that emerged from the interview data. Afterwards, a set of content analysis categories was created in which all the emerged categories were included. As Table 3 and 4 show, the first column displays the theoretical concept of the study, the second column the interview question with the keys concepts or categories in bold, and the third column offers a summary of the sub-categories or themes identified in the data set.

*Table 3 Summary of Steps in Qualitative Data Analysis for the Sense of Competence*

Theoretical concepts of the study	Interview questions with primary category in bold	Categories derived from interview data
Sense of Competence	Q 1. Would you like to describe to me some of the <b>joys and pleasures</b> of parenting?	<ul style="list-style-type: none"> <li>- sharing love</li> <li>- spend quality time with the child</li> <li>- providing education/values</li> <li>- enjoyment child's accomplishments/development</li> </ul>
	Q 2. Could you tell me what are some of the <b>challenges</b> of the parenting?	<ul style="list-style-type: none"> <li>- difficulty to manage family tasks/time</li> <li>- difficulty to discipline</li> <li>- <b>difficulty to assure child's well being</b></li> <li>- difficulty to provide education /values</li> <li>- difficulty in managing societal influences</li> </ul>
	Q 3. Could you <b>describe your parenting now</b> that you have an ill child ?"	<ul style="list-style-type: none"> <li>- illness as additional challenge</li> <li>- difficulty to accept/deal with illness</li> <li>- difficulty to manage tasks/time of family</li> <li>- <b>difficulty in handling the ill child's behaviour</b></li> <li>- struggle with siblings' rivalry</li> <li>- illness controls family</li> <li>- taking action/feeling responsible</li> <li>- parenting manageable despite illness</li> <li>- feeling responsible/concerned</li> <li>- feeling closer to the child</li> <li>- able to treat the child normally</li> <li>- able to adapt</li> <li>- richness of illness</li> <li>- different parenting</li> </ul>
	Q 4. How do you <b>perceive your role</b> as mother/father in this particular situation?	<ul style="list-style-type: none"> <li>- caregiver</li> <li>- teacher/guide</li> <li>- financial provider</li> <li>- support/help provider</li> <li>- being polyvalent</li> </ul>

*Table 4 Summary of Steps in Qualitative Data Analysis for Perception of Uncertainty*

Theoretical concepts of the study	Interview questions with primary category in bold	Categories derived from interview data
Perception of uncertainty	Q 6. Are there some issues with respect to parenting, now with an ill child, that remain <b>ambiguous or confusing</b> to you?	<ul style="list-style-type: none"> <li>- illness expected course/prognosis</li> <li>- interpreting treatment symptoms</li> <li>- questioning what's best for child</li> <li>- role performance/discipline</li> <li>- role performance itself</li> <li>- future way of living</li> </ul>
	Q 7. When you feel ambiguity or confusion, <b>how do you cope</b> with such feelings?	<ul style="list-style-type: none"> <li>- talking to others</li> <li>- living day by day</li> <li>- avoiding to think</li> <li>- wishful thinking</li> <li>- seeking information/understanding</li> <li>- asking questions</li> <li>- doing something different</li> <li>- seeking assurance</li> <li>- seeking help support</li> <li>- seeking solutions</li> <li>- crying</li> </ul>
	Q 8. Would you like to talk to me about your <b>life in the future</b> ?	<ul style="list-style-type: none"> <li>- bright/promising future</li> <li>- unwilling to vision the future</li> <li>- complicated/uncertain future</li> <li>- looking forward for normal life</li> </ul>
	Q 9. If you think of all that happened to you as a parent since your child was diagnosed, what kind of <b>support and advise</b> would be the most helpful for other parents who find themselves in your situation?	<ul style="list-style-type: none"> <li>- being positive</li> <li>- trusting health care team</li> <li>- living day by day</li> <li>- being available</li> <li>- believing in God</li> <li>- hoping</li> <li>- treating the child normally</li> <li>- talking to others</li> <li>- asking for help/support</li> </ul>

Though such a classification it was possible to look for recurrent categories in the data and record the frequency of category appearance among the participants (Jones, 1985). An example of a recording frequency of categories among the participants is provided in Appendix VIII. This process was checked for trustworthiness by another coder who verified such a content analysis of data. Next, a comparison of categories and category frequency among mothers and fathers was pursued to examine similarities and/or differences among them. The qualitative analysis and identified patterns were also compared with the quantitative findings, leading to an integration across data sources.

#### *3.1.4.2. Analysis of questionnaires*

Both descriptive and inferential statistical methods were employed for the analysis of the questionnaires. The Parenting Sense of Competence Scale (PSOC) was analysed by calculating the means and standard deviations for mothers and fathers using SPSS 12.0 for Windows.

The Uncertainty Orientation measures were analyzed with the help of a consulting statistician from the Social Science Centre of the University of Western Ontario who had access only to an aggregate data set and the guide of the Manual and Practice Materials for Scoring Need for Uncertainty (Sorrentino, et al., 1992). Regarding the analysis of the projective test data, stories were scored as containing uncertainty-resolution imagery if they met criteria which participants strive to resolve uncertainty about themselves or their environment (Sorrentino, et al., 1992). Stories were scored regarding the following categories: 1) Need for Uncertainty Imagery (NI), 2) Doubtful Imagery (DI), 3) Unrelated Imagery (UI). If the story has been scored DI or UI then no more scoring was possible. If

the story has been scored NI then the story was examined for the following subcategories such as: 1) Stated Need to Master (N) if a person in the story states a desire to reach the goal of mastering or approaching uncertainty, 2) Instrumental activity (I+/?/-) that includes a person's activities to approach or resolve uncertainty, 3) Goal Anticipation (Ga+, Ga-) in which a person anticipates goal failure or attainment, 4) Blocks In The Person (Bp) or In The World (Bw) if the progress of goal directed activity is hindered in some way, 5) Nurturant Press (Nup) when personal forces in the story aid the person in reaching his/her goal of resolving uncertainty (this is a very rare subcategory), 6) Thema (Th) when the entire story is an elaboration of the behavioural sequence involved in resolution of uncertainty. Once the scoring for the story was complete, numeric values were assigned. Stories scored UI received a numeric value of -1. Stories scored DI received a value of 0. Stories scored NI received a value of +1 with an additional +1 assigned for each subcategory present. Scores from each story were summed and standardized to form a total nUncertainty score. An example of a parent's answered projective test is also provided (Appendix VII). Scores from the 21-item acquiescence-free authoritarian scale were summed and standardized. Certain items (i.e., 7, 8, 11, 12, 14, 15, 17, 18, 19 and 21) were reversed keyed. To form the resultant measure, the standardized authoritarianism score was subtracted from the standardized score for nUncertainty. Participants who were scored high on the resultant measure (i.e., high in nUncertainty, low in authoritarianism) were categorized as uncertainty-oriented, and those who were scored low on the resultant measure (i.e., high in authoritarianism, low in nUncertainty) were categorized as certainty-oriented.

### ***3.1.5. Research Validity***

In this section I briefly discuss issues of reliability and validity in terms of the qualitative data analysis pursued. Such issues in terms of the quantitative data were already discussed in those sections.

Since qualitative research is subjective, interpretive, and is concerned with individuals and the meaning of experiences in their lives, traditional ways of thinking about reliability and generalizability are inadequate for such research (Janesick, 2000; Lincoln & Guba, 1985; Morse & Richards, 2002). Put differently, in qualitative research, concerns about validity are more important than reliability, since the researcher does not attempt to offer insights into generalizable patterns but instead, attempts to arrive at an interpretation that accurately reflects or assesses the specific concept that the researcher is attempting to measure in terms of the population studied (Huitt, 1998; Wiersma & Jurs, 2005).

Hence, validity in qualitative research has to do with description and explanation and whether or not the explanation fits the description; in other words, looking for the credibility of such an explanation (Janesick, 2000). Similarly, validity has to do with the integrity, the character, or the quality of data and its interpretation, and that should be assessed in relation to the purposes and circumstances of the research being conducted (Brinberg & McGrath, 1985; Eisenhart & Howe, 1992; Lincoln & Guba, 1985).

According to Lincoln and Guba (1985), the following aspects of trustworthiness need to be examined: “truth value” and “applicability” which are effectively analogous to internal validity and external validity. The “truth value” of a study corresponds to its credibility and accuracy of the research and the interpretations drawn from it. In this

study, credibility and accuracy were obtained by prolonged engagement and triangulation (Lincoln & Guba, 1985). By a prolonged period of engagement, we refer to the care the researcher exercised to minimize the respondents' feelings of unease and lack of trust that could have influenced the research in negative ways. The researcher tried to establish a first contact with the parents through the telephone and in turn, adapted to the interview situation once in the respondents' setting. By interviewing the parents in person, they could also develop a sense of trust with the researcher. Accordingly, much care was exercised by the researcher in allowing for enough time for the interview and in supporting the parents in all possible ways as not to make them feel devalued or threatened by the research situation.

Credibility of the research was also obtained by examining each interview transcript for regularity and consistency of patterns that come to define a subject position. That way, the data and its interpretation can be considered to express authenticity (Schostak, 2006). In doing this, the interpretation of the data can be said to be credible to those who provided the data (Eisenhart & Howe, 1992). While no member-checks were possible to assure further credibility, by having another researcher examine the sensibility of my interpretations of the data and the emergent category labels, some credibility could be assured.

Next, the technique of triangulation is a mode of improving the probability that results and interpretations will be found credible (Lincoln & Guba, 1985). Triangulation is based on the premise that multiple methods of data collection and analysis provide cross-data consistency, credibility, validity, quality and more confidence in findings rather than one single data collection and analysis method (Eisenhart & Howe, 1992;



Wiersma & Jurs, 2005). Furthermore, triangulation has been generally considered a process of using multiple perceptions to clarify meaning, rather than seeking a singular truth (Patton, 2002; Stake, 2000). Triangulation serves to clarify the meaning by identifying and interpreting the different ways the phenomenon is being seen from different angles and perspectives (Eisenhart & Howe, 1992; Miles & Huberman, 1984; 1994; Stake, 2000). In this study, triangulation was obtained by combining different data collection modes (i.e., interviews and questionnaires) and analysis methods (i.e., qualitative and quantitative approaches).

“Applicability”, the second aspect of trustworthiness analogous to external validity, refers to the transferability of the results to similar contexts. As Lincoln and Guba (1985), suggest it is the researcher’s responsibility to provide the data base that makes transferability judgments possible on the part of potential appliers. Accordingly, one may see links between the data presented here and other similar situations while generalizations per se, however, are not the goal. Instead, through a rich description of the time and context in which the study was conducted, the reader is offered with enough detail to judge the interpretations as sensible and possibly applicable to other situations, and hence, allowing for some elaboration.

### ***3.1.6. Summary***

To summarize, a very specific sample of parents with a child struggling with leukemia was studied and evaluated via questionnaires and a semi-structured interview. A description of the instruments, the procedure, the data collection and analysis was offered. The validity of the quantitative measures were explored in the sections

describing those instruments. A section on validity in terms of the qualitative data explained the triangulation of data collection and analysis methods pursued, which offer trustworthiness and credibility to the study overall, and the interpretations drawn. Finally, it became possible to answer the research questions and to disclose results that are presented in the next chapter.

## **CHAPTER IV**

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## **4.1. Presentation of Results**

### **4.1.1. Chapter Overview**

This chapter presents the results with respect to the parents' sense of competence and orientation towards uncertainty as gathered through the questionnaires and the interviews. The chapter is divided in three sections. The first section presents the quantitative results from the Parenting Sense of Competence questionnaire, followed by a description of the interview data. Then, a description of parental gender differences and/or commonalities is offered, followed by a comparison and integration of quantitative and qualitative findings. Similarly, the second section begins with the presentation of findings gathered through the Uncertainty Orientation measures followed by a description of the themes related to uncertainty that emerged from the interview data. Next, a discussion concerning gender differences and/or similarities is provided, followed by a comparison and integration of the findings from the data gathered through the Uncertainty Orientation measures and the interviews. The third and last section concludes with a presentation of findings regarding the relationship between parents' sense of competence and uncertainty orientation.

## ***4.2. The Parents' Sense of Competence in Light of their Child's Chronic Illness***

In this section, both quantitative and qualitative descriptive findings are presented to illustrate parents' sense of competence while parenting a child with leukemia.

### ***4.2.1. Presentation of Results of the Parenting Sense of Competence Scale (PSOC)***

The aim in this section is to present the data from the Parenting Sense of Competence Scale (Johnston & Mash, 1989) a questionnaire that was completed by both parents. PSOC total scores were calculated by summing the 16 items that loaded on the two factors: Efficacy and Satisfaction that make up that scale. Means and standard deviations for the Efficacy factor, Satisfaction factor and PSOC total scores for mothers and fathers are presented in Table 5.

*Table 5 Means and Standard Deviations for Total PSOC Scores among the Parents*

	Total PSOC Scores		Satisfaction		Efficacy	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Mothers	42.39	10.16	26.16	9.23	16.22	4.22
Fathers	44.39	11.35	25.94	8.05	18.44	5.96

No significant differences are evident in terms of the total PSOC scores for the Satisfaction and the Efficacy factors among parents. As discussed in the section of the description of the instruments (Chapter III) participants who score 16 points manifest a very low sense of competence whereas participants who score 96 points reveal a very high sense of competence. As shown, the mothers' (42.39) total PSOC score and the fathers' (44.39) total PSOC score suggests that both parents' perception of competence was average. With respect to the Satisfaction factor (9 items), subjects who score with a minimum of 9 points manifest a very low satisfaction whereas subjects who score a maximum of 54 points exhibit a high sense of satisfaction. As shown both parents (mothers' with 26.16 and fathers with 25.94) displayed an ordinary sense of satisfaction. Regarding the Efficacy factor (7 items) subjects who score with a minimum of 7 exhibit a very low efficacy, whereas those who score 42 manifest a high efficacy. Again, both parents' scores (mothers with 16.22 and fathers with 18.44) demonstrate that their level of efficacy situates itself as average. The findings suggest that the parents we sampled in this study scored average in terms of their sense of efficacy and satisfaction with parenting, and hence, appear typical of parents at large.

#### ***4.2.2. Presentation of the Interviews Results on Parents' Sense of Competence***

This section presents the results from the parents' interviews with the aim to further explore and reveal how parents perceive their competence in terms of parenting their child with leukemia. Answers to the following four questions from the interview are pulled together and analysed for this objective.

- Question 1: "Would you like to describe to me some of the joys and pleasures of parenting?" This question was intended to lead parents to express their contentment and satisfaction as a parent in general.
- Question 2: "Could you talk to me about some of the challenges of parenting?" This question was designed to reveal the parents' perceptions of difficulties and/or problems regarding their parenting.
- Question 3: "Could you describe to me your parenting now that you have an ill child?" This question gets at parents' perception of parenting now that they have an ill child in the family.
- Question 4: "How do you perceive your role as a mother/father in this particular situation?" This question was intended to lead parents to discuss the different ways they perceive their roles as a parent within the family's daily routine while facing their child's chronic illness.

A common set of categories were identified across the parents both in terms of their general sense of competence and their sense of competence in light of their child's illness. Parents' responses to the interview questions 1 and 2 noted above, shed light on

the ways parents perceived their competence within their family prior to the child's chronic illness and for that purpose were analyzed together. The findings are summarized and presented in Table 6.



*Table 6 Parents' Sense of Competence prior to their Child's Chronic Illness*

Sense of Competence	Common categories	Parents (%)	Parents (n = 36)
Pleasures of parenting	Enjoyment of the child's accomplishments/development	55.5	20
	Spending quality time with the child	47.2	17
	Sharing love	38.8	14
	Providing education/values	19.4	7
Challenges of parenting	Difficulty to discipline	36.1	13
	Difficulty to provide education/values	33.3	12
	Difficulty to manage family tasks/time	25	9
	Difficulty to manage societal influences	11.1	4
	Difficulty to assure the child's well being	5.5	2

As Table 6 shows, the parents' sense of competence in general, is mostly manifested by a feeling of great pleasure and satisfaction of being a parent. In fact, categories such as "enjoyment of the child's accomplishments/development" (55.5%), "spending quality time with the child" (47.2%) and "sharing love" (38.8%) show high percentages among the parents. "Enjoyment child's accomplishment/development" entails the parents' great contentment in seeing their children grow up healthy and happy, learn and discover new things day by day and become confident and independent in life. To them, that brings an immense gratification and fulfillment and makes them believe they have done an excellent job as a parent. The following interview sections further underline the parents' responses and views in terms of "enjoyment of the child's accomplishments/development":

*It is nice to see the evolution, when they learn, when they appreciate, when they catch on to new things, when they discover new things...see them grow up. Sometimes looking back to a week ago or a month ago and you see something new, you know, a new amount of independence, when I see them grow up and become more independent, and learn new things and be more self confident, it shows that they are going to be good people. (F7)*

*C'est de voir l'évolution de mes enfants, de voir selon leurs qualités et leurs défauts qu'est-ce qu'ils peuvent devenir plus tard, de voir leur évolution, c'est ça le moment le plus plaisant pour moi. (M11)*

Similarly parents manifest a considerable desire to spend quality time with their children, make them happy, and in general, to maintain a lifestyle suitable to accommodate different family activities that lead to children's enjoyment.

*Spend time with my kids, we aren't parents that like to go out, when we travel we like to be with our kids, we are not parents that like to be alone or travel by ourselves, we always travel with them, we share a lot of time with them, everything we do is always with them, being with them. (F1)*

*Le temps passé avec les autres, le soir et les fins de semaine, les activités, les devoirs, sont les petits moments qu'on passe avec les autres. (M18)*

*...playing with my kids, enjoying and having fun with them, teaching riding the bicycle that's fun, it's nice to see that, be able to go anywhere at any time that's being parent want to get a movie go to movie. (F3)*

The category of "sharing love" that represents the parents' expressions of feelings, positive emotions and affection towards their children is also manifested with a quite high percentage among parents (38.8%). Several quotes from parents underline such unconditional love towards the children and the way this feeling manifests itself. Some quotes are presented as follows:

*Sometimes you know [it's] just one gives a kiss to each other, nice words just "I love you" things that make you feel good. (M1)*

*Le matin quand je vais les réveiller et ils me donnent des bécus puis qu'ils me disent bonjour maman, puis que je leur donne un million de bécus avant d'aller se coucher.....n'importe quoi, pour moi être mère c'est une grande joie toute la journée. (M8)*

Differently, for some other parents the satisfaction and joy of being a parent were manifested through the category of “providing education/values” to their children. The “providing education/values” category underlines the parents’ pleasure but also commitment to teach their children the right values about life and guide them through and towards the best choices:

*Finalemment de leur donner tout ce qu'on peut pour la propre vie avec un bagage, un meilleur bagage qu'on peut leur donner. (M<sub>2</sub>)*

*Le plaisir, c'est de leur montrer des expériences qu'on a eues dans notre vie, dans notre passé, les éduquer de la même façon et de leur montrer des belles choses, mieux qu'on a appris, de les guider dans une bonne direction. (F<sub>15</sub>)*

However, some other parents perceive their competence with respect to their effectiveness and achievement to accomplish their parental roles. They expressed themselves mainly in terms of their difficulties and challenges encountered while parenting their children. In fact, categories of “difficulty to discipline” (36.1%), and “difficulty to provide education/values” (33.3%), are presented with the highest percentages among parents, followed by the categories of “difficulty to manage family tasks/time” (25%), “difficulty to manage societal influences” (11.1%), and “difficulty to assure the child’s well being” (5.5%). Discipline refers to the parents’ ability to teach children self-control and obedience and to follow rules and regulations established in the family. As summarized in Table 6 a considerable number of parents (36.1%) perceive the discipline of their children as very challenging and find it difficult to make their children understand and put in action the fundamental principles of authority leading to frustration for some.

*It's always repeating, you know, like you always have to say the same thing and sometimes you think that they could understand the first time like an adult, but they can't because they are children. So, it's day by day pick up this, pick-up that, do this, do that....What is it I can do to make them understand, it's not always easy to find the way to follow rules. (M<sub>1</sub>)*

Also, a number of parents discussed the challenge of providing their children with a good education and values while also protecting them from negative influences and inappropriate societal values.

*I think the most important thing is to give them the right values so that they can be independent to make the right choices. This is a challenge for parents. (F<sub>6</sub>)*

*On vit en société et, en société, il peut y avoir des comportements qu'on aime pas beaucoup et que les enfants, veut, veut pas, ils vivent plus en société qu'avec nous, donc c'est ça qu'est difficile, le travail qu'on doit faire. (M<sub>9</sub>)*

The “management of family tasks/time” (25%) is perceived by parents as another difficult and demanding task. It is defined as the parent’s ability to organize family life, set up priorities for task execution, to be present and active with the child, and keep a balance within the family daily routine:

*C'est le contre temps, le contre temps que se soit d'ordre moral, ou d'ordre matériel cause le plus gros problème parce que tout le monde fait son effort d'être bien, mais c'est le contre temps c'est-à-dire l'incompréhension ou le manque de temps, ou quand on n'a pas suffisamment les moyens pour faire aboutir des projets. (F<sub>9</sub>)*

*It is a delicate balance of work, family, and personally, the difficult choices you have to make some time. The balance, keeping the harmony for the family, the couple also, isn't always easy. (F<sub>12</sub>)*

To conclude a very small number of parents manifested their difficulties in terms of “assuring the child’s well being” (5.5%), which refers to the parents’ perception of inability to control their child’s physical well being and healthiness, as the following two mothers stated. It suggests that most parents were able to simply talk about parenting without thinking about the challenge experienced now due to having an ill child.

*The health you have now... I think this is the most challenging thing, for me I think is the health, the well being, the control on it. (M<sub>6</sub>)*

*....and being in health which is a big challenge for me. (M<sub>17</sub>)*

In sum, although parents were asked to talk about both the pleasures and the challenges experienced while parenting in general, parents were found to talk more often about their pleasures and joys of being a parent, rather than their encountered challenges of their parenting.

#### ***4.2.2.1. The parents' perceptions of competence in parenting a child with leukemia***

Now in an attempt to reveal and describe the parents' perceptions of competence while parenting their child with leukemia, answers to the third and fourth interview questions were gathered and analyzed together. The results are summarized and presented in Table 7.

*Table 7 The Parents' Perceptions of Competence in Light of their Child's Illness*

Sense of Competence	Common categories	Parents (%)	Parents (n = 36)
Perceptions of difficulty	Illness as an additional challenge	36.1	13
	Difficulty to accept/deal with illness	27.7	10
	Difficulty in managing tasks/time of family	16.6	6
	Difficulty in handling the ill child's behaviour	13.8	5
	Struggle with the siblings' rivalry	11.1	4
	Illness controls family	5.5	2
Perceptions of ability/efficacy to cope	Taking action/feeling responsible	33.3	12
	Parenting manageable despite illness	22.2	8
	Feeling competent	22.2	8
	Feeling responsive/concerned	19.4	7
	Feeling closer to the child (positive of illness)	11.1	4
	Able to treat the child normally	8.3	3
	Able to adapt	5.5	2
	Richness of illness (positive of illness)	5.5	2
	Different parenting	5.5	2
Role perceptions (as)	Caregiver	30.5	11
	Teacher/guide	16.6	6
	Financial provider	13.8	5
	Support/help provider	11.1	4
	Being polyvalent	5.5	2

As Table 7 shows, the findings are divided into three major categories such as “parents’ perceptions of difficulty”, “parents’ perceptions of ability/efficacy to cope” and “parents’ perceptions of role”. It is interesting to note that both perceptions of difficulty and ability/efficacy to cope were noted about the same number of times among the parents. Such a finding demonstrated that parents equally perceived their competence as unsatisfactory in terms of difficulties and problems but they also perceived themselves as equally capable and skilled to cope with such a challenging situation.

Talking about the parents’ perceptions of difficulty, “illness as an additional challenge” was noted the most often, having the highest percentage (36.1%). More than one third of the parents perceived the illness as an additional challenge, followed closely by a sense of “difficulty to accept/deal with the illness” (27.7%). In fact, parents appeared to perceive their child’s chronic illness as an additional and constant preoccupation leading to non stop worries and hence as being very demanding and a challenge to the daily family routine, as the following quotes revealed:

*Is the worries you wake-up in the morning and you are thinking, I hope today she hasn't any fever, or cold because then you know that the sickness will be back and this is something you don't want. (M<sub>1</sub>)*

*It is a constant preoccupation for me to make sure that he is not get sick, he is in contact with other children, he is going to school, his immune system is too low. I have to be careful, I have to always aware all the time. (M<sub>1</sub>)*

*Les médicaments, les traitements, la chimiothérapie, la physiothérapie tout ce que comporte avec les à cotés de la maladie, son moral....(M<sub>7</sub>).*

It is obvious that dealing with such a challenging situation parents often perceive themselves as powerless and incapable to help and support their child or to have control of their own life inside and outside the family, as some of the parents stated:

*On se sent impuissante, on peut pas aider la personne, l'impact c'est qu'on se sente impuissante, on n'est plus capable de gérer ça. (M<sub>3</sub>)*

*I feel life just slipping away, I do not feel the control in a way that I would like to ....at work, at home with my wife, with my friends. (F<sub>6</sub>)*

The category “difficulty to accept/deal with illness” (27.7%), is defined as the parents’ difficulty to admit and understand their child’s illness and what it may now imply for them as a family. Some parents found insupportable and painful to have a child with a chronic illness. Therefore, feelings of frustration and dissatisfaction are not surprising. The following quotes offer a better sense of such as challenge:

*La pire chose que peut arriver à un parent, tant qu'on n'a pas vécu ça on peut pas savoir, mais la pire chose qui peut arriver c'est quand on a un enfant qui tombe malade, c' était absolument dévastateur comme expérience. (F<sub>2</sub>)*

*C'est un processus difficile, dévastateur, quand vous découvrez qu'un membre de la famille et beaucoup plus particulièrement un des vos enfants est atteint d'une maladie à cinquante pour cent incurable, voire fatale, c'est plus que dévastateur parce que comme si tous vos projets sont tombés à l'eau et ce ne sont pas juste des projets matériels, c'est surtout une affection parentale, un enfant c'est une partie de vous, c'est plus que vous et puis quand on découvre quelque chose comme ça, c'est une très grande catastrophe. (F<sub>9</sub>)*

Some other parents perceived the coping with the various illness demands as very heavy and difficult in terms of both the physical and emotional involvement such demanded of them, as shown in the following quotes:

*C'est difficile pour moi, chaque jour je pense à mon garçon qu'est malade de leucémie .par exemple je sais que chaque mercredi il fait des traitements pour moi c'est pas encore fini, c'est difficile pour moi.....la gestion de la maladie, l'enfant est là, il faut aller à l'hôpital, prendre ses médicaments. (F<sub>5</sub>)*

*Trop chargé moralement....physiquement ça dépend des moments, ça dépend des journées, mais moralement veut, veut pas c'est beaucoup parce que notre cerveau ne s'arrête pas, même plus, donc face à ça moi je trouve que....surtout le moral on est là, on pense, en même temps c'est tout ça en même temps, et en même temps on est comme abattus...on est là on a pris beaucoup de coups....c'est lourd. (M<sub>9</sub>)*



Another challenge to the parents' sense of competence is their perceived "difficulty to manage tasks/time of family" (16.6%) which refers to the parents' efforts to organize the family routine, the daily activities, and to respond and fulfill each family members' needs within such a challenging and life-threatening situation. Parents perceived themselves as inexperienced in their endeavour to do their best to build and maintain harmony, to give stability and assure functioning of the family. The quotes below show this kind of parental perception:

*Is the bigger challenge because you need somebody to stay....and also there are other kids and you need to take care. (F<sub>12</sub>)*

*Plus de temps à consacrer, lourd dans toute l'organisation familiale, en plus de s'occuper de l'enfant. (M<sub>18</sub>)*

*Right now I am stuck with a twelve hours shift, it takes me one hour to go and one to coming back, and when I am working at night I only have three hours[off] sleep, so.....lack of time....the job is very hard and I cannot spend time with my kids and by having lack of sleep I am losing my temperament. Right now, that's the way it is right now. (F<sub>3</sub>)*

Another important issue are the parents' perceived difficulty in handling both the ill child's and the siblings' behaviour. These difficulties are represented by the categories of "difficulty in handling the ill child's behaviour" (13.8%) and "struggle with the siblings' rivalry" (11.1%). Parents expressed themselves most in terms of their inability to understand and interpret their ill child's unusual behaviour due to the medical treatment. They often felt confused and unable to distinguish if their child is acting in order to obtain a favour or if the illness related treatments affect child's behaviour, as a father affirmed:

*...because of the leukemia we do not know how to take her now is it because of the medications [that she] is like that? it's very tough to distinguish because all those medications she is taking they give to her very bad moods swings, it isn't funny any more, and you do not know how to take her sometimes. (F<sub>3</sub>)*

On the other hand, dealing with the siblings' rivalry and opposition, contributes to the parents' perceptions of dissatisfaction, guiltiness and sometimes their feeling of being manipulated by their children. The following quote underlines these dynamics further:

*I find [it] difficult with my kids because they are great, great actors and that's tough. General I am feeling manipulated, they act differently when I am there or when I am not there, that's [the] tough part, sometimes we feel guilty to spend much time in the hospital but I cannot do nothing about it . I have not time, I spend all my time with her in hospital I feel guilty and the small one she uses us [that in her] advantage, this is the tough part.... (F<sub>3</sub>)*

As shown dissatisfaction and feelings of guilt are often mentioned together with a constant preoccupation in treating siblings alike. This father (F<sub>3</sub>) is mostly worried about attending equally to the ill child and his or her siblings. Consequently, parenting becomes very stressful due to the continuous worries, anxieties and sometimes the inability to establish rules and discipline. To conclude, certain parents, even though a very small number (5.5%), talked about how sometimes their child's illness appears to control the entire family. Such was discussed primarily in terms of lack of freedom, social isolation from friends or relatives, and the difficult choices parents and siblings have to make due to the ill child's vulnerable physical condition. Here is what a father stated:

*We cannot go out somewhere like we used to do, like vacation, we have to isolate a lot because he is sick....we cannot see people, we can see them outside, but you cannot go to the public pool or public[place] so [that is another thing] that you have to be more isolate, lack of freedom. (F<sub>18</sub>)*

Briefly, parents' perceptions of unsatisfactory or not good enough competence were expressed primarily in terms of difficulties and problems related to parenting their ill child. The categories that were linked to parents' negative sense of competence were "illness as an additional challenge", "difficulty to accept/deal with illness", "difficulty to

manage tasks/time of family”, “difficulty in handling the ill child’s behaviour”, “struggle with the siblings’ rivalry”, and “illness controls family”.

On the other hand, when parents perceived themselves as competent and skilled in facing their child’s chronic illness expressed themselves in a positive and constructive way. The categories that were linked to these positive parental perceptions are presented as follows: “taking action/feeling responsible” (33.3%), “parenting manageable despite illness” (22.2%), “feeling competent” (22.2%), “feeling responsive/concerned” (19.4%), “feeling closer to the child” (11.1%), “able to treat the child normally” (8.3%), “able to adapt” (5.5%), “richness of illness” (5.5%) and “different parenting” (5.5%).

As shown, the “taking action/feeling responsible” (33.3%) category is presented with the highest percentage among the positive perceptions and represents the parental awareness and consciousness of doing everything possible for both the child’s and the family’s benefits and well being. The following passages illustrate examples of parents’ perceptions in terms of responsibility while dealing with their child’s chronic illness:

*Ma responsabilité c’était de prendre charge des enfants à la maison pour avoir une vie presque normale. (F<sub>2</sub>).*

*I think that I am a responsible person, I did that all my life, more now with my children and I am responsible for everything in [the] house. (M<sub>1</sub>)*

*I feel responsible for the others members of the family. (M<sub>16</sub>)*

*C’est moi qui suis le pilier de tout ça les enfants sont toujours tournés vers moi, et si moi je ne suis pas disponible ils vont peut-être aller vers leurs père, mais c’est moi qui ai la responsabilité des médicaments et toutes les responsabilités face aux enfants. (M<sub>18</sub>)*

Similarly, parents’ perceptions of their “parenting as manageable” (22.2%), further underlines their sense of effectiveness and success in performing their roles as a parent.

In fact, some parents perceive their parenting as identical to before and not influenced or

affected by the presence of their child's chronic illness. Differently, for some other parents, "manageable" parenting refers to their attempts to parent as before, to keep the same rules and family routine as it used to be and to adapt regulations and daily routine in a way that parenting can still be successful.

*...but being a parent is the same as it was a year ago, two years ago she was born, is taking care of her, playing with her... (M<sub>1</sub>)*

*I try to keep it the same, with more flexibility you know rules are rules and they are there for a reason, It is not hard for me, no, I have not problem with that, teaching them and showing them what it has to be done it is not a problem. (F<sub>7</sub>)*

Although the category of "feeling capable"(22.2%) refers to the parents' perception of themselves as skilled, confident and able to perform their parental roles, the "feeling responsive/concerned" (19.4%) category underlines both the parents' interest and ability to respond immediately to their child's and/or family needs.

*I think when I go to bed at night for me I did a good job, the best I could.. (M<sub>1</sub>)*

*.....as I said do not forget anything, not to and also to keep the other activities, going to work, being a good worker for others also so in terms of parenting is to keep everything ok. (F<sub>12</sub>)*

*Je me perçois comme bonne, moi je me trouve bonne par rapport à Samuel ; j'étais toujours là presque, c'était moi toujours à l'hôpital, si Samuel tombe malade n'importe quand c'est moi qui va à l'hôpital, tous les soins, c'est moi Je pense que mon rôle comme mère avec lui, j'ai le bien réussi, oui. (M<sub>11</sub>)*

*I was born mother, I was born mother because I feel that I do things right regarding children and this feeling is inside. (M<sub>17</sub>)*

*Je me sens comme une maman poule maintenant, on est toujours là, les oreilles, les yeux, on est en l'alerte, on est plus attentif, on est plus compréhensif, on essaie de comprendre chaque enfant....être mère ça veut dire faire face à ça, de gérer ça et de mettre l'ambiance vraiment agréable. (M<sub>5</sub>)*

As shown from the above quotes, parents believed themselves to have the required qualities to accomplish their parental roles no matter what challenges they face. These qualities included being attentive and ready to act, having developed an intuition and

perception of ways of dealing with and responding to the family's needs and also being able to cope with the daily problems accordingly.

Another positive parental perception of competence was manifested by a small number of parents such as the "ability to treat the child normally" (8.3%) and the "ability to adapt" (5.5%). This finding suggests that despite the challenging circumstance, some parents do not change significantly their parental style and discipline, while some others demonstrate their ability to adapt and familiarize themselves with such a difficult situation. Hence, it is noteworthy to mention that some parents, even if only a small number of them, were able to see something positive in their child's chronic illness. In fact, categories such as "feeling closer to the child" (11.1%) and "richness of illness" (5.5%) highlight such positive parental perceptions. This kind of sense of competence is related to the parents' feelings of having acquired more expertise, knowledge and maturity through the challenges they faced. The following passages make evident the parent's personal experiences and ways of knowing that they acquired:

*But in one way, I am sure we learned about ourselves, we learned about our kids, and I think, for sure, I do not want to say that but really learned something more.*  
(M<sub>6</sub>)

*Moi je pense qu'on a eu une expérience qui nous a donné des outils qu'on n'avait pas avant, plus de sagesse, plus de recul, peu importe quel problème au travail, à la maison.* (F<sub>8</sub>)

These quotes indicate that despite the troubling situation, parents acquired specific parenting skills such as more self-knowledge which they highly value. They attribute some positive value to this experience of coping with their child's illness. Accordingly, a mother (M<sub>6</sub>) stated: "*we learned about themselves, we learned about our kids.*" It made

them closer to each other and develop stronger relationships with more sensitivity and comprehension of the situation as the mother above said:

*Parce qu'on dit que toujours il y a un coté positif à chaque chose, c'est difficile de dire qu'il y a un coté positif dans sa maladie, mais oui il y en a un, le coté positif c'est qu'on a appris à mieux se connaître. Veut, veut pas, aujourd'hui la vie c'est vite, puis je trouve qu'on a appris à mieux se connaître. Il y a eu un bon rapprochement avec mon fils, c'est ça...c'est un gros changement. (M<sub>7</sub>)*

To conclude, the category of “different parenting” (5.5%) underlines parents’ perception of their parenting as having changed, but not necessarily in terms of becoming more difficult or challenging. Perception of parenting as different may be considered in terms of priorities to set-up, reorganizing the family life or reconsidering existing values and principles within the family that used to be important prior to the child’s illness. The following quotes offer examples:

*Très différent, premièrement ses priorités changent beaucoup lorsque que t'apprends le diagnostic donc c'est complètement une autre vie, c'est vraiment complètement une autre vie, c'est différent c'est sûr. (M<sub>7</sub>)*

*....it is just different... it is just different...I do not see it as more difficult, I do not see [it as] better....just different. (F<sub>18</sub>)*

Considering now, how parents perceive their roles while parenting their chronically ill child, the perception of a parental role as “caregiver” (30.5%) appears as the most often quoted among parents, followed by the perception of their role as “teacher/guide” (16.6%), as “financial provider” (13.8%) as “support/help provider” (11.1%) and as “being polyvalent” (5.5%). The role as “caregiver” is defined as the parents’ perceptions of aptitude to fulfill and respond to the family and the child’s needs. See the following comments:

*It's taking care of her., bringing her to the hospital every month ..eh....nothing else.. eh.. to love her, to make her understand that we are there for her. (M<sub>1</sub>)*

*Fait que mon rôle à moi c'était vraiment d'essayer de voir que tout ça passe bien que tout le monde soit correct. Mon rôle c'est de m'assurer que tout monde va bien, que personne ne manque de rien alors essayer de manager tout ça en même temps. (M<sub>14</sub>)*

These passages underline the parents' abilities of taking care of their children by caring and loving them, by supporting them, and also by trying to provide all the necessary in order to cope well with such difficult circumstances in the family. In another way some parents perceive their role as "teacher/guide" which refers to their ability to both educate and coach the child through its development, and to promote the child's achievements and self-sufficiency in life.

*My role as a father for [my] child is [giving]... support ... love... teaching... leading by example. (F<sub>7</sub>)*

*Je suis capable de rendre les enfants le plus vite autonome mon rôle c'est que quand on fait les devoirs ensemble, ce n'est pas pour m'arranger qu'elle a une bonne note, mais de m'arranger pour qu'elle soit capable de donner une bonne réponse d'elle même. (F<sub>8</sub>)*

Although some fathers perceive their role as the one who brings money home and assures for the financial well being in the family, some others also referred to their role in supporting and helping the child or other family members when needed. To conclude, a very slight number of parents perceive themselves as "being polyvalent" (5.5%) most in terms of being able to execute other different tasks and functions or to be able to switch easily their assigned parental roles, as a father stated:

*Je pense que, comme mère, je touche un petit peu à certains points comme ça comme jouer le rôle de l'infirmière, la psychologue. Mon rôle est très polyvalent, plus approfondi comme parent. (M<sub>7</sub>)*

*On avait un même rôle, tu t'occupe de Julie aujourd'hui, demain c'est moi, on change, pas plus papa que maman avec des tâches particulières on est polyvalent. (F<sub>8</sub>)j*

In summary, the interview data shows that the parents' perceptions of competence entail both negative and positive elements. With respect to the negative perceptions, dealing with illness" related issues were most often referred to as challenging by the parents. Parents experienced emotional strain, fear and constant worry about their child with leukemia but also about the rest of the family. The dissatisfaction of the parents was evident in their difficulties to manage illness, organize family's daily routine and handle the ill child's and sibling's behaviour. Parents revealed their dilemmas in terms of making the right decisions and they also manifested their difficulties to discipline and be firm with both ill child and siblings. Equally, parents also perceived themselves as competent in terms of different aspects of their parenting. Positive and satisfactory perceptions of competence were most often manifested by the parents' feelings of responsibility, competency and responsiveness for the ill child and family. Besides, the parents' perceptions of role in this challenging circumstance further underlines their sense of competence and efficacy to accomplished their parental duties.

### ***1.2.3. Parental Gender Differences and/or Similarities in terms of Sense of Competence***

The purpose of this section is to present the differences and/or similarities among mothers and fathers with respect to their sense of competence while parenting with a chronically ill child in the family. Results are summarized and presented in Table 8.



*Table 8 Parental Gender Differences and Similarities of Sense of Competence in Parenting a Child with Leukemia*

Sense of Competence	Common categories	Mothers (%)	Mothers (n = 18)	Fathers (%)	Fathers (n = 18)
Perceptions of difficulty	Illness as an additional challenge	44.4	8	27.7	5
	Difficulty to accept/deal with illness	16.6	3	38.8	7
	Difficulty to manage tasks/time of family	16.6	3	16.6	3
	Difficulty in handling the ill child's behaviour	16.6	3	11.1	2
	Struggle with the siblings' rivalry	16.6	3	5.5	1
	Illness controls family	5.5	1	5.5	1
Perceptions of ability/efficacy to cope	Taking action/feeling responsible	38.8	7	27.7	5
	Parenting manageable despite illness	16.6	3	27.7	5
	Feeling competent	44.4	8	0	0
	Feeling responsive/concerned	16.6	3	22.2	4
	Feeling closer to the child (positive of illness)	11.1	2	11.1	2
	Able to treat the child normally	11.1	2	5.5	1
	Able to adapt	5.5	1	5.5	1
	Richness of illness (positive of illness)	5.5	1	5.5	1
	Different parenting	5.5	1	5.5	1
Role perceptions (as)	Caregiver	33.3	6	27.7	5
	Teacher/guide	5.5	1	27.7	5
	Financial provider	0	0	27.7	5
	Support/help provider	5.5	1	16.6	3
	Being polyvalent	5.5	1	5.5	1

As shown, Table 8 summarizes parental sense of competence based on gender and on three different parental perceptions; the negative perceptions of competence (dissatisfaction), the positive perceptions (ability/satisfaction), and the parents' perceptions of their role. It is very interesting to note that among the negative parents' perceptions of competence there are only two major differences between mothers and fathers, while other minor differences can be observed. Precisely, a major difference exists in terms of the category "illness as an additional challenge" with mothers scoring higher (44.4%) than fathers (27.7%). Conversely, in the "difficulty to accept/deal with illness" category, fathers scored higher (38.8%) as opposed to mothers (16.6%).

With respect to the positive perceptions of competence, more similarities than differences are apparent among mothers and fathers with the exception to the category of "feeling competent" which was only referred to by mothers (44.4%). Taking into consideration the parents' perceptions of their role, only fathers referred to their role as financial provider for the family (27.7%), while mothers never mentioned such for themselves. Furthermore, fathers scored higher in their perceptions of role as provider of help/support (16.6%) and as being a teacher/guide for the child (27.7%) as compared to the mothers' scores (5.5% each).

In sum, although more similarities than differences in terms of sense of competence between mothers and fathers are apparent, gender differences are only pronounced for the category of "feeling competent" which refers only to mothers, and the perception of role as "financial provider" perceived only by fathers.

#### ***1.2.4. Comparison of Findings between the Parenting Sense of Competence Scale and the Interviews***

As previously presented, the results from the Parenting Sense of Competence Scale (Total PSOC score) suggest that the parents' perception of competence was average in terms of efficacy and satisfaction. On the other hand, the interview data regarding the parents' sense of competence prior to their child's chronic illness (see Table 6), revealed that the parents' pleasures of parenting (feelings of satisfaction) are higher represented as compared to the parents' encountered challenges (feelings of efficacy) were referred to more often than the challenges they faced as parents.

However, with respect to the parents' perceptions of competence in light of parenting now with a chronically ill child in the family, perceptions of pleasures were now equally often noted as the challenges they faced. It can be assumed, that with an ill child, among the parents studied here, the negative perceptions and challenges became more pronounced yet did not outnumber the positive effects, suggesting a balance between the two.

This finding supports evidence that the parents' sense of competence revealed through the interview data was also average, showing no extreme unbalance between the positives and negatives related to parenting. A particular consideration should be given to the parents' positive perceptions of their role and the manner such reflects feelings of efficacy and satisfaction about being a parent. Overall, results from the Parenting Sense of Competence Scale and the interviews lead to similar conclusions regarding the parents' sense of competence that was revealed as ordinary and as equally satisfactory and dissatisfactory now in the family with a chronically ill child.

### ***4.3. The Parents' Uncertainty Orientation***

The aim in this section is to present both quantitative and qualitative descriptive findings as gathered from the Uncertainty Orientation measures and the interviews. Firstly, the quantitative findings demonstrate both the parents' and couples' orientation towards uncertainty. Next, the interview data will offer another interpretation of the parents' uncertainty orientation while parenting now in a family with an ill child.

#### ***4.3.1. A General Presentation of Parents' Uncertainty Orientation***

Table 9 summarizes the findings of the parents' uncertainty orientation in our sample assessed through the application of the Uncertainty Orientation measures (Sorrentino, et al., 1992). This table shows that the parents were almost equally divided among the profiles; uncertainty- certainty- and moderate-oriented. Moderate-oriented parents, those who cope with uncertainty in a very inconsistent manner, represent a somewhat larger group (38.9%), followed by the certainty-oriented group (30.6%), and the uncertainty-oriented parents (30.5%).

*Table 9 The Parents' Uncertainty Orientation Profiles*

	Mother (n = 18= 50%)	Father (n = 18=50%)	Total (n = 36=100%)
Uncertainty-oriented (%)	8.3 (n=3)	22.2 (n=8)	30.5 (n=11)
Certainty-oriented (%)	16.7 (n=6)	13.9 (n=5)	30.6 (n=11)
Moderate-oriented (%)	25 (n=9)	13.9 (n=5)	38.9 (n=14)
Total (%)	50	50	100

As shown, half of the mothers scored as moderate-oriented (25%), whereas almost half of the fathers scored as uncertainty-oriented (22.2%). Specifically, the data shows that among the parents classified as moderate-oriented (38.9%), mothers account for 25% whereas fathers for 13.9%. In contrast, among the uncertainty-oriented parents (30.5%), fathers represent 22.2% compared to 8.3% mothers, clearly a somewhat inverted pattern.

#### ***4.3.2. The Uncertainty Orientation Profile among the Couples***

This section presents the parents' uncertainty orientation profile within the same parental couple. Given the fact that both parents are involved in different parenting activities with their chronically ill child, it is interesting to look at the similarities and/or differences towards uncertainty orientation inside each couple. Table 10 offers a summary of the uncertainty orientation profile of the parents, based on Sorentino's measures.

*Table 10 The Uncertainty Orientation Profiles among Couples*

Parental couples	Mother's uncertainty orientation profile	Father's uncertainty orientation profile	Couple's uncertainty orientation profile
M <sub>1</sub> -F <sub>1</sub>	U.O.	U.O.	U.O.
M <sub>2</sub> -F <sub>2</sub>	U.O.	U.O.	U.O.
M <sub>3</sub> -F <sub>3</sub>	C.O.	M.O.	Mixed
M <sub>4</sub> -F <sub>4</sub>	M.O.	U.O.	Mixed
M <sub>5</sub> -F <sub>5</sub>	C.O.	C.O.	C.O.
M <sub>6</sub> -F <sub>6</sub>	M.O.	U.O.	Mixed
M <sub>7</sub> -F <sub>7</sub>	M.O.	U.O.	Mixed
M <sub>8</sub> -F <sub>8</sub>	M.O.	U.O.	Mixed
M <sub>9</sub> -F <sub>9</sub>	C.O.	C.O.	C.O.
M <sub>10</sub> -F <sub>10</sub>	M.O.	U.O.	Mixed
M <sub>11</sub> -F <sub>11</sub>	M.O.	M.O.	M.O.
M <sub>12</sub> -F <sub>12</sub>	U.O.	U.O.	U.O.
M <sub>13</sub> -F <sub>13</sub>	C.O.	M.O.	Mixed
M <sub>14</sub> -F <sub>14</sub>	M.O.	M.O.	M.O.
M <sub>15</sub> -F <sub>15</sub>	C.O.	C.O.	C.O.
M <sub>16</sub> -F <sub>16</sub>	M.O.	C.O.	Mixed
M <sub>17</sub> -F <sub>17</sub>	C.O.	C.O.	C.O.
M <sub>18</sub> -F <sub>18</sub>	M.O.	M.O.	M.O.

Note. M=mother; F= father; U.O.= uncertainty-oriented; C.O.= certainty-oriented; M.O.= moderate-oriented

As shows in Table 10, 10 out of 18 couples share the same uncertainty orientation profile, whereas 8 out of 18 couples have a mixed uncertainty orientation profile. The 10 out of 18 couples who share the same uncertainty orientation profile can be divided into three (3) uncertainty-oriented, four (4) certainty-oriented and three (3) moderate-oriented. Eight out of 18 couples show a dissimilar uncertainty orientation profile, the so called mixed. Among the mixed couples the majority (5 couples out of 8) is composed of a moderate-oriented mother and an uncertainty-oriented father. One couple consists of a

moderate-oriented mother and a certainty-oriented father; and the two other couples have a certainty-oriented mother and a moderate-oriented father. Of interest is the fact that none of the couples have an uncertainty-oriented partner paired with a certainty-oriented. Hence, opposite uncertainty orientation profiles did not pair within the studied couples. These findings allow for the hypothesis that partners in relationships do not necessarily pair with a dissimilar behaviour. However, when considering this similarity in the studied couples, it is important to take into account the possibility that parents may influence each other in terms of performing their roles as well as making decisions regarding their child's life. In addition, within the confines of this study, it can be hypothesized that a coexistence of different uncertainty-orientation profiles within a parental couple would probably hinder harmonious and cooperative parenting.

#### ***4.3.3. Presentation of the Interviews Results on Parents' Uncertainty Orientation***

We now explore in what ways the interview data offers further insights into the parents' uncertainty orientation profile while parenting in a family with a chronically ill child. Answers to the following four interview questions are pulled together and analyzed for this purpose.

- Question 6: "Are there some issues with respect to parenting, now with an ill child, that remain ambiguous or confusing to you?" This question was aimed to lead parents to talk about the different kinds of uncertainty that they may experience, especially with respect to their parenting under such challenging circumstances.

- Question 7: “When you feel ambiguity or confusion, how do you cope with such feelings?” This question was intended to lead parents to discuss their strategies of coping under uncertainty.
- Question 8: “Would you like to talk to me about your life in the future?” This question gets at parents’ perception of their future given their current situation with a child with leukemia.
- Question 9: “If you think of all that has happened to you as a parent since your child’s diagnosis, what kind of support and advice would be the most helpful for other parents who find themselves in your situation?” The advice offered by the parents offers further insights into their coping strategies that are also influenced by their uncertainty orientation.

Based on the analysis of the parents’ answers to the above interview questions, three kinds of uncertainty were identified among the parents’ experience of parenting a child with leukemia; uncertainty related to illness, uncertainty related to parenting uncertainty and uncertainty in terms of the future. A recurrent set of categories regarding the parents’ strategies of coping and perceptions about their life in the future also emerged from the data.. The findings are summarized and presented in Table 11.



*Table 11 The Parents' Experiences of Uncertainty, Coping and Future Perceptions*

Perceptions of Uncertainty	Common categories	Parents (%)	Parents (n = 36)
Illness	Illness expected course/prognosis	61.1	22
	Interpreting treatment symptoms	8.3	3
Parenting	Questioning what's best for child	19.4	7
	Role performance/discipline	19.4	7
	Role performance itself	16.6	6
Future	Future way of living	25	9
Coping Strategies	Talking to others	41.6	15
	Living day by day	36.1	13
	Avoiding to think	19.4	7
	Wishful thinking	16.6	6
	Seeking information/understanding	16.6	6
	Asking questions	11.1	4
	Doing something different	8.3	3
	Seeking assurance	5.5	2
	Seeking help/support	5.5	2
	Seeking solutions	5.5	2
	Crying	5.5	2
Parents' Future Perceptions	Bright/promising future	55.5	20
	Unwilling to vision the future	16.6	6
	Unable to vision the future	11.1	4
	Complicated/uncertain future	11.1	4
	Looking forward for normal life	8.3	3

First and foremost, as shown in Table 11 parents' expressed their feelings of uncertainty mainly in terms of their child's illness course and prognosis (61.1%) as compared to the future (25%) and parenting uncertainties in general (19.4%). This finding suggests that illness related uncertainty is of most significant concern. Parents express feelings of insecurity, fear, anxiety and constant worries concerning their child's illness itself, the illness evolution and possible complications. In fact, uncertainty regarding "illness course/prognosis" (61.1%) and "interpreting treatment symptoms" (8.3%), resulted from a lack of understanding illness course, incapacity to assess improvements or treatment related symptoms and inability to gain perspective on the illness severity. The following quotes provide some illustrations of that kind of uncertainty expressed by the parents:

*We didn't know what is going to happen next, because we didn't have enough information about leukemia, this was a big uncertainty then. (F<sub>10</sub>)*

*It's the sickness we don't want [the sickness] to come back, for the moment that scares me the most. (M<sub>1</sub>)*

*Les inquiétudes face à la maladie. on était incertain que ça va passer, ça va guérir au complet? Il y des rechutes qui peuvent arriver...qu il n'y pas de rechute, la plus grosse crainte est la rechute, ça arrive aussi beaucoup, on voit beaucoup qu'on fait la rechute après plusieurs années, même quand les années vont passer. (M<sub>2</sub>)*

*Maintenant que j'ai un enfant malade j'ai des incertitudes par rapport à la fin de traitement; il y a toujours l'incertitude que reste là...et ça pourrait arriver que après deux ans, ce soit autre chose, ça peut avoir une rechute et ça va plus loin le processus.....c'est la peur que ça revienne plus tard. (M<sub>14</sub>)*

*We still have fears that [the] sickness may come back. That is the big fear because I do not know, if it comes back I am not sure if we have the resources to do it as well because I know that it will be harder. So I have uncertainty and that's about the only fears I have...if the sickness comes back... (M<sub>12</sub>)*

As shown, once the child is diagnosed with such a life-threatening illness, parents' uncertainty never goes away and is always coupled with a constant preoccupation, stress and fear about their child's long-term health conditions and the possibilities of a relapse.

Hence, living with such a sustained uncertainty causes further ambiguity or confusion concerning the parents' ability to perform their perceived roles as a parent. Some parents manifested uncertainty about being able to make good decisions and right choices for the best of their child as summarized by the category label "questioning what's best for child" (19.4%). Similarly, some other parents perceive uncertainty about how well they can perform and control their parental roles referred to here as the "role performance/discipline" (19.4%) and the "role performance itself" (16.6%). The following quotes put in evidence the parents' uncertainties regarding parenting their ill child in terms of these themes:

*C'est ne plus à savoir ce qui est la meilleure chose pour mon enfant, qu'est-ce je peux faire. (M<sub>14</sub>)*

*Je dirais que l'incertitude a un impact dans mon rôle comme père, je ne suis jamais sûre à cent pour cent si telle manière, c'est correct, ce n'est pas correct, je me questionne définitivement. (F<sub>11</sub>)*

*Des fois....je me dis est-ce que je suis une bonne mère pour elle, est-ce que je réagis correctement avec elle? Toutes ces questions me viennent des fois. (M<sub>13</sub>)*

*It's more discipline that....is something....because you always think "am I doing the things in a right way? or your neighbours are they doing better than you are doing? I have to be more strict and for that is hard because then you think ...is the discipline and when to say no or yes. (M<sub>16</sub>)*

Furthermore, parents needed to know the lasting effects of such a life-threatening illness, particularly the impact that illness may have on the child's future development and quality of life. This kind of uncertainty was expressed by parents through the category of the "future way of living" (25%). The following quotes show how parents talked about it:

*Comment que ça va se dérouler, puis ça va être quoi qui va arriver à la fin, ça va être quoi à la fin? la seule ambiguïté qui peut rester, le point d'interrogation majeur, c'est qu'est-ce qui va arriver à Gabriel plus tard?. (F<sub>2</sub>)*

*C'est l'inconnu que me fait peur.....après sa maladie, comment il va être.....on sait pas.....est-ce qu'il va être capable, normal une fois grandi.....est-ce qu'il va être bien? (M<sub>5</sub>)*

With respect to the parents' strategies of coping with uncertainty, the findings revealed the presence of two major coping approaches. A confronting approach with strategies that aimed to resolve uncertainty, and an avoidance approach that aimed to keep clarity and avoid uncertainty; it was observed that parents who try to resolve ambiguity generally are challenged with keeping optimism and hope and yet, are motivated to maintain a positive environment at all times. They are primarily motivated to seek clarity through mastery of uncertainty by adopting an overall information-seeking behaviour such as "talking to others" (41.6%), "seeking information/understanding" (16.6%), "asking questions" (11.1%), "seeking solutions" (5.5%) and "seeking help/support" (5.5%). As shown, the most frequently mentioned coping strategy was talking to others such as a spouse, family members or relatives, friends, or with other parents of children with leukemia. For the parents "talking to others" strategy served both to relieve emotional distress, and to enable parents to decide how to better manage a current or impending difficulty. In other words, by expressing their worries and fears parents feel comforted. They may also receive support and positive feedback from others, ideas for solutions to their problems or even different perspectives for dealing with their challenges. For example some parents said:

*By talking to each other we make the good decisions. (F<sub>3</sub>)*

*I just communicate with somebody and discuss, it could be with the nurse, the doctor, with my wife, just the family, my parents, uncles, just talk to somebody, a second opinion, a third opinion. (F<sub>12</sub>)*

*Je veux parler avec mon mari et avec mon garçon aussi, on va parler ensemble. (M<sub>15</sub>)*

Hence, coping strategies such as “seeking information/understanding” (16.6%), and “asking questions” (11.1%) make evident the parents’ desire to understand the unknown and their openness to new and/or unusual information. For example, one father adopted a more systematic information seeking approach and attended seminars and other presentations that could offer clues and potential solutions to his problem.

*On a fait beaucoup de lectures sur les différents sujets en psychologie, on a participé aux sessions...parlé de notre enfant...c’est un genre de séminaire...ça nous a aidé beaucoup. (F<sub>14</sub>)*

Equally, a mother found very beneficial to seek out new information from the health care professionals or other experienced people in order to gain knowledge and mastery over her uncertain situation. Here is what she said:

*In the beginning I did not know much about cancer but, with the [help of the] team from the Sainte-Justine hospital who passed books and [the help of] other people too, I realized that I have all the chances to gain the game ... (M<sub>17</sub>)*

A comparable behaviour among some other parents in their coping strategy of “asking questions”. Parents looked for answers to their doubts and ambiguities, further understanding of the problem, and more knowledge and assurance from the health specialists. One father affirmed, “*je demande toujours les infirmiers comment ça va, je pose toujours des questions*” (F<sub>16</sub>). Similarly, a mother sought out the doctors for information and showed confidence in the medical staff as she affirmed:

*Moi je pose beaucoup de questions, à l’hôpital on est suivi à la lettre, on est bien encadré, on peut appeler, je m’arrête pas à ça, aussitôt que je sens l’incertitude je pose des questions et ils vont me répondre. (M<sub>18</sub>)*

The “seeking solutions” (5.5%) and “seeking help/support” (5.5%) strategies were equally adopted by a small number of parents. They manifested their ability to look for the possible solutions to their problems. One father stated “*essayer de trouver la*

*meilleure chose qui peut nous faire sortir de cette ambiguïté” (F<sub>9</sub>)*. Similarly, they demonstrated their capability and positive attitude to accept any kind of support and help from others and to use the available community sources, as these two mothers affirmed, *“je demande de l’aide” (M<sub>5</sub>)*, and *“I start going to see a therapist to help me out” (M<sub>12</sub>)*.

However, different coping strategies were adopted by parents when they perceived uncertainty as a threat, preferring a day-to-day philosophy. Hence, they mainly embraced the “living day by day” (36.1%), “avoiding to think” (19.4%), “wishful thinking” (16.6%) and “doing something different” (8.3%), followed by “seeking assurance” (5.5%), and “crying” (5.5%). As demonstrated, the most frequently manifested strategy among the avoidance coping was the “living day by day” (36.1%). It can be assumed that taking each day as it comes rather than projecting in the future, helped parents to cope with uncertainty by protecting them from possible future deceptions and undesirable outcomes. Also, they try to focus on the present and enjoy the moment at its fullest. Parents preferred to deal with problems when they actually arose.

*I try to take it day by day, there is a lot of uncertainty, a lot of confusion about sickness. (F<sub>1</sub>)*

*...just to take one day at the time. (M<sub>16</sub>)*

*Il faut vivre peut-être les instants quand ils se présentent au niveau de ma fille, au niveau de la maladie, jour par jour, puis vivre pleinement tous les jours les bonnes choses, et puis quand arrivera une certaine situation, on fait face..... d’oublier cette maladie- là. (F<sub>15</sub>)*

In addition, not thinking about the threatening situation or doing something different helps parents to distract and reduce their anxiety and stress. For instance, some parents try to disengage their thoughts from the problem by introducing elements of physical

work such as gardening, taking care of everyday tasks, listening to music, or reading, thus avoiding uncertainty.

*[I keep myself busy]. The garden when the summer comes around. I do a lot of digging...[sometimes] going through the closet throwing things ...I am more [attracted] to the [physical] kind of [work]. I plan to do something physical, something better, that works. (M<sub>3</sub>)*

*Mais parfois l'incertitude ça vient, ma stratégie est que je fais d'autre chose, si je travaille je mets mon baladeur, c'est pas la musique seulement, c'est la lecture juste pour évaporer les mauvaises idées...pour moi c'est un jour à la fois...combien de temps il reste à vivre, je ne sais pas. (F<sub>3</sub>)*

Furthermore, a small number of parents adopted strategies such as “seeking assurance” (5.5%) and “crying” (5.5%). The strategy of “seeking assurance” refers to the parents’ attempts and desire to find out positive outcomes in terms of their child’s illness course and prognosis that can reduce their anxiety and fear. This strategy may also helped to keep hope and positivism regarding the evolution of the illness and to master uncertainty, as the following passages affirmed:

*J'ai hâte d'avoir les résultats et de m'assurer que tout c'est correct. (F<sub>8</sub>)*

*J'ai eu quand même besoin de trouver quelque chose qui m'assure qu'on est dans la bonne direction...j'ai eu besoin de me confirmer que c'était guéri. (M<sub>8</sub>)*

Few also referred to strategies they invoked to release emotional strain such as “crying” (5.5%). This strategy helped parents to ease painful or distressing emotions as a father stated: “*I will cry in front of them, I will express my feelings in front of them*”. (F<sub>1</sub>). Finally, parents who adopt a “wishful thinking” (16.6%) coping strategy, demonstrate their tendency to keep hope and an optimistic belief that “the best” will happen. This coping strategy enables parents to bear the burdens of such a life-threatening illness, as a father said: “*just hoping that everything goes right*” (F<sub>4</sub>)

At this point, it is noteworthy to mention that the majority of parents (55.5%) manifested a very positive attitude and optimism about their future. This is an interesting finding, since the parents' experienced uncertainty is intense and long lasting. Yet, having such a positive outlook and constructive vision for the future increases parents' confidence and enables them to better cope with such a challenging and detrimental situation. The following quotes clearly show parents' confidence and optimistic perceptions about their future:

*I see my future even better I will travel more, my kids will become older, everything will go well, I do not see any problem. I think it gets easier and easier day by day now. I think everything is going to be better, so if I picture my future what I see is just my son growing up. (F<sub>7</sub>)*

*I always close my eyes and I picture my self and my children being happy running around, having a good life, not having a lot of money, but I picture me self and my family positive. I know inside me that everything goes to be fine and we will go to be happy, that's why when I close my eyes I see my children running, and running, and running and playing I always do that, I close my eyes and I can see that. (M<sub>4</sub>)*

*L'avenir, on a le choix de bien l'envisager. Il faut partir de la position de la réussite, il faut se dire on va réussir et on réussira, on est plein d'enthousiasme. Puis on essaie d'oublier ce qui c'est passé, parce que ça nous sert à rien de penser à ça, et puis il faut envisager la vie positivement, du bon côté. (F<sub>9</sub>)*

*Moi personnellement je m'arrête, je pense, je fais un scénario, j'essaie de m'imaginer comment ça va être dans cinq ans, dans dix ans, à vingt ans peut-être, on commence à se préparer pour arriver ...je pense toujours positif. (M<sub>17</sub>)*

In spite of such positive perceptions about the future, some parents were found to be “unwilling” (16.6%) or “unable” (11.1%) to envision the future, while others perceived their future as “complicated/uncertain” (11.1%). These parents seem to be more pessimistic, vulnerable and powerless given their constant worries about the negatives that could re-surface:



*Ça va être plus difficile, inquiétant, c'est sûr qu'on peut avoir des moments de bonheur, mais toujours avec la crainte que ça peut finir, ça peut changer en une fraction de seconde, un jour ça va bien, puis le lendemain ça peut aller mal on pourrait jamais dire c'est réglé, ça va toujours être présent. (M<sub>2</sub>)*

*I do not think that the future must be easier, I think whenever your children are getting older, your problems getting much worse. (M<sub>10</sub>)*

Furthermore, certain parents did not desire to make projections about their future or were simply not able to talk about it. One mother affirmed: *"je suis moins portée à penser loin...je préfère penser comme ça plutôt que penser loin"*(M<sub>7</sub>). Another parent manifested an incapacity to visualize his future by affirming how uncertainty overshadows family's life and impedes parents from making plans for the future.

*I cannot see that, because she goes bad tomorrow, she had a fever, you do not know, now planning to go to the Disneyland and for me, is too far away, I have to cancel the trip in last minute because of [her], you do not know what may be happen, [I] cannot think too far away. (F<sub>3</sub>)*

In addition, a quite small number of parents (8.3%), wished to return back to the regular life they used to have prior to the child's illness. It shows the parents' tiredness to deal with such a challenging situation and their strong desire that this will be over soon, as the following mothers said:

*Hoping that things go easier, that we will be back to the regular routine, regular health, regular ups and downs. it will be just nice, of course you can have your business, but not because you have to go to the hospital, not because you have scheduled appointments you seeing the same people for the same reason....that's [what] I would like. (M<sub>3</sub>)*

*I think we just want to go back to what we used to be just to take care your self, to establish the family. (M<sub>6</sub>)*

Another element that needs to be considered here is the advice the parents offered for others in similar circumstances. In fact, the findings confirmed previous results regarding the parents' coping strategies and also offered an additional elucidation about what parents consider as more effective and helpful in dealing with such a challenge and

uncertainty. The most common advice are as follows: “being positive” (30.5%), “living day by day” (25%), “talking to others” (19.4%), “hoping” (16.6%), “asking for help/support” (13.8%), “being available” (13.8%) and “believing in God” (11.1%). In particular, “being available” refers to the parents’ ability to be present for the child when needed and to spend quality time with their children, as the following quotes demonstrated:

*I tell them enjoy them because your kids are healthy now so enjoy them, people with sick kids like Annick enjoy them, go to different places, go for walks, spent time with them, be available, do little things. (F<sub>3</sub>)*

*Being with the kids, being with them, talking, doing things with them.....it's really being with them, not just talking, really being in relationship ...it's just being with them, sharing with them. I do not say being with them hours and hours, it's not the quantity is the quality to be with your kids and enjoy that, really enjoy that.. (M<sub>6</sub>)*

*Be able to give as much time to your child.. (M<sub>16</sub>)*

In addition, parents recommended that “believing in God” (11.1%), may help to better cope with such challenging circumstances. The following passages underline the parents’ tendency to rely on faith to cope:

*C'est à Dieu qu'il faut demander. (M<sub>13</sub>)*

*Si on s'approche à Dieu, et si on croie que Lui il va nous aider. (F<sub>17</sub>)*

*trusting God because He has all the things in His hands. (M<sub>17</sub>)*

To summarize, the interview data revealed that in certain times parents are positively and highly motivated to confront and resolve ambiguity by seeking clarity through mastery of uncertainty. They mostly seek out further information and understanding from talking to others, asking questions and seeking solutions to the problem. However, other times, parents coped by adopting a day-to-day approach and an avoidance behaviour. They also

appear to prefer to ignore uncertainty which they probably perceive as a danger and consequently, they try to keep it away from their lives.

#### ***4.3.4. Parental Gender Differences and/or Similarities in terms of Orientation towards Uncertainty***

The intention in this section is to show the differences and/or the similarities between mothers and fathers with respect to their orientation towards uncertainty. Results are summarized and presented in Table 12.

*Table 12 Parental Gender Differences and/or Similarities within Uncertainty Orientation*

Perceptions of Uncertainty	Common categories	Mothers (%)	Mothers (n = 18)	Fathers (%)	Fathers (n = 18)
Illness	Illness expected course/prognosis	66.6	12	55.5	10
	Interpreting treatment symptoms	5.5	1	11.1	2
Parenting	Questioning what's best for child	22.2	4	16.6	3
	Role performance/discipline	16.6	3	22.2	4
	Role performance itself	16.6	3	16.6	3
Future	Future way of living	27.7	5	22.2	4
Coping Strategies	Talking to others	44.4	8	38.8	7
	Living day by day	16.6	3	55.5	10
	Avoiding to think	33.3	6	5.5	1
	Wishful thinking	22.2	4	11.1	2
	Seeking information/understanding	11.1	2	22.2	4
	Asking questions	16.6	3	5.5	1
	Doing something different	11.1	2	5.5	1
	Seeking assurance	5.5	1	5.5	1
	Seeking help/support	11.1	2	0	0
	Seeking solutions	0	0	11.1	2
	Crying	5.5	1	5.5	1
Parents' Future Perceptions	Bright/promising future	55.5	10	55.5	10
	Unwilling to vision the future	16.6	3	16.6	3
	Unable to vision the future	5.5	1	16.6	3
	Complicated/uncertain future	16.6	3	5.5	1
	Looking forward for normal life	11.1	2	5.5	1

As shown, more similarities than differences were found between mothers and fathers in terms of their perceptions of uncertainty, coping strategies, and perceptions of the future. Specifically, the collected data demonstrate that mothers and fathers scored quite similarly in terms of their perceptions of uncertainty about their child's illness, their parenting performance and future quality of life. With respect to parents' coping with uncertainty, although mothers and fathers favour similar coping strategies, there are some variations between them. In fact, a major difference between mothers and fathers is evident in terms of "avoidance" and "taking one day at a time". Mothers, more often than fathers, tended to behave with an "avoidance" approach to deal with uncertainty showing a higher score in terms of "avoiding to think" (33.3%) and in terms of "doing something different" (11.1%). In contrast, fathers more often referred to "living day by day" (55.5%), compared to mothers (16.6%).

Furthermore, concerning parents' perceptions about their life in the future, an important similarity between mothers and fathers was evident. Both parents equally express high levels of optimism (55.5%) in terms of their perceptions about the future. Similarly, parents scored equally with respect to "unwilling to vision the future" perception (16.6%). However, a difference between parents was manifested with respect to being "unable to vision the future" and with "complicated/uncertain future". Although fathers scored higher (16.6%) as compared to mothers (5.5%) in being "unable to vision the future", conversely mothers scored higher (16.6%) as opposed to fathers (5.5%) in their perception of a "complicated/uncertain future".

Now, in an attempt to provide further elucidation of findings, the next section examines links between patterns found from the Uncertainty Orientation measures and the interviews.

#### ***4.3.5. A Comparison of Findings between the Uncertainty Orientation Measures and the Interviews***

As presented earlier, results from the Uncertainty Orientation measures yielded three different uncertainty orientation profiles among parents: the uncertainty-, certainty- and the moderate-oriented. Specifically, the moderate-oriented parents were determined to be the largest group 38.9% followed with almost equal percentages of the certainty-oriented 30.6% and the uncertainty-oriented group 30.5%. Also, it was found that among mothers half were classified as moderate-oriented, whereas among fathers almost half were classified as uncertainty-oriented. In terms of the parents' uncertainty orientation within the same couple, findings revealed that a majority of the couples have a similar uncertainty orientation profile between partners. Of interest was the fact that none of the studied couples entailed partners of opposite uncertainty orientation profiles.

On the other hand, results from the interviews yielded the coexistence of two distinct uncertainty orientation profiles among parents; a seeking information type and an avoidance behaviour approach. Although this finding agrees somewhat with the quantitative results regarding the two different and opposite profiles; the uncertainty and certainty-oriented, it supports evidence that parents mostly represent the moderate-oriented profile.

#### ***4.4. The Relationship among Parents' Sense of Competence and Uncertainty Orientation***

The purpose in this section is to clarify the relationship between the sense of competence and uncertainty orientation among parents. Results are presented in Table 13.

Uncertainty-oriented parents had slightly lower scores in the total PSOC (40.27) than certainty- (44.54) and moderate-oriented (44.93), whereas certainty- and moderate-oriented parents were similar. Also, uncertainty-oriented parents scored lowest on the Satisfaction factor (21.27) as compared to certainty-oriented (30.09) and moderate-oriented (26.64). In contrast, for the Efficacy factor, uncertainty-oriented parents achieved the highest score (19.00) as compared to certainty- (14.45) and moderate-oriented (18.28).

*Table 13 Comparison of Mean Scores and Standard Deviations of a Total PSOC, Satisfaction and Efficacy Scores Among Uncertainty-, Certainty- and Moderate-Oriented Profiles*

	Total PSOC Scores		Satisfaction		Efficacy	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Uncertainty-Oriented	40.27	12.64	21.27	8.54	19.00	5.54
Certainty-Oriented	44.54	8.47	30.09	7.73	14.45	3.58
Moderate-Oriented	44.93	10.78	26.64	7.79	18.28	5.41

The Mann-Whitney test – a non-parametric measure–based on a rank calculation was conducted in order to determine if these differences are significant or not (Siegel & Castellan, 1988). The Mann-Whitney U test was chosen because the present study employs small and independent samples. The uncertainty- and certainty-oriented groups were compared followed by the comparison of the certainty- and moderate-oriented groups in terms of the total PSOC score, Efficacy and Satisfaction factor. Null ( $H_0$ ) and  $H_1$  Hypothesis were postulated and the appropriate calculations conducted. The results are presented in Table 14 and Table 15:



*Table 14 A Comparison of the Uncertainty-Oriented and Certainty-Oriented Group With Efficacy, Satisfaction and Total PSOC Scores*

	Uncertainty Orientation	N	Mean Rank	Sum of Ranks	U	Null ( $H_0$ ) and $H_1$
Sum of Efficacy	Uncertain	11	14.59	160.50	26.5	Reject of the $H_0$
	Certain	11	8.41	92.50		
	Total	22				
Sum of Satisfaction	Uncertain	11	8.50	93.50	27.5	Reject of the $H_0$
	Certain	11	14.50	159.50		
	Total	22				
Sum of Competence PSOC	Uncertain	11	9.36	103.00	37	No reject of the $H_0$
	Certain	11	13.64	150.00		
	Total	22				

*Table 15 A Comparison of the Certainty-Oriented and Moderate-Oriented Group With Efficacy, Satisfaction and Total PSOC Scores*

	Uncertainty Orientation	N	Mean Rank	Sum of Ranks	U	Null ( $H_0$ ) and $H_1$
Sum of Efficacy	Certain	11	9.77	107.50	41.5	No reject of the $H_0$
	Moderate	14	15.54	217.50		
	Total	25				
Sum of Satisfaction	Certain	11	14.95	164.50	55.5	No reject of the $H_0$
	Moderate	14	11.46	160.50		
	Total	25				
Sum of Competence PSOC	Certain	11	12.68	139.50	73.5	No reject of the $H_0$
	Moderate	14	13.25	185.50		
	Total	25				

As shown in Table 14, the data from the Mann-Whitney test revealed no significant differences between uncertainty- and certainty-oriented parents regarding their perception of competence (Total PSOC). However, it is interesting to note that with respect to the Efficacy and Satisfaction factor, the Mann-Whitney test suggests that the difference between the uncertainty- and certainty-oriented groups is significant. It means that uncertainty-oriented parents scored significantly higher on the Efficacy factor (14.59) than certainty-oriented parents (8.41). In contrast, certainty-oriented parents scored significantly higher on the Satisfaction factor (14.50) than uncertainty-oriented parents (8.50). This makes sense in light of our qualitative interview analysis. Uncertainty-oriented parents who seem to have an “action” approach and keep hoping, trust others, seek solutions to resolve uncertainty and work on it feel higher in efficacy. Yet such is hard work emotionally and hence they rate lower on satisfaction. In contrast, certainty-oriented parents who generally avoid dealing with illness feel satisfaction, but they score

low on efficacy. With respect to the comparison between the certainty- and the moderate-oriented groups, Table 15 suggested no significant differences were found from the Mann-Whitney test on (Total PSOC), on the Efficacy and the Satisfaction factors.

#### ***4.4.1. Summary***

With respect to the parents' sense of competence with parenting a child with leukemia, findings revealed an average sense of competence entailing both positive and negative elements with no significant differences among parents. Regarding parents' orientation towards uncertainty, qualitative findings demonstrated the presence of different coping strategies adopted to resolve or to avoid uncertainty and in agreement with the two and opposite uncertainty orientation profiles; the uncertainty- and certainty-oriented. While quantitative findings revealed moderate-oriented parents as the largest group among the three uncertainty-oriented profiles, qualitative findings support such an evidence. In conclusion, quantitative findings revealed a significant relationship among uncertainty-oriented parents and their perception of Efficacy and among certainty-oriented parents and their perception of Satisfaction. Uncertainty-oriented parents displayed a higher score in Efficacy, whereas certainty-oriented parents displayed a higher score in Satisfaction.

**CHAPTER V**

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## **5.1. Discussion**

### **5.1.1. Chapter Overview**

The previous chapter offered a description of the parents' perception of competence and orientation towards uncertainty in light of having a child with leukemia in the family. The first part of this chapter focuses on an interpretation of the results in light of the literature reviewed at the beginning in terms of the parents' sense of competence and the parents' different perceptions of uncertainty and their orientation towards uncertainty while caring for a chronically ill child. Differences and/or similarities due to gender with respect to the variables of sense of competence and uncertainty orientation are also discussed. Equally, interpretative comments are presented with respect to the relationship between the parents' sense of competence and uncertainty orientation. Remarks on the limits of the study are then discussed, followed by the study's implications for educational programs and intervention. The chapter concludes with recommendations for further research.

## ***5.2. Mothers' and Fathers' Sense of Competence of Parenting a Chronically Ill Child***

This first research question focused on mothers' and fathers' perceptions of expertise and know-how in performing their parental roles while caring for their child with leukemia. The results from the parents' questionnaires shown no significant differences between mothers' and fathers' perceptions of competence. This finding is congruent with earlier studies that demonstrated that mothers and fathers correlated significantly in their assessment of sense of competence and did not differ in their cognitions about their parenting either (Baker & Heller, 1996; Johnston & Mash, 1989; Harvey, 1998; Hoza et al., 2000; Rogers & White, 2000). In fact, it is interesting to note that the parenting competence scores in this study are similar to those of parents who do not struggle with the additional parenting challenges caused by suddenly facing a chronic illness in the family among one of the children. It suggests that somehow they are representative of the parents at large and not distinguishable based on that scale from parents of healthy children.

Interestingly, the interview data reveals many gender commonalities in both perceptions of difficulty and ability of parenting a child with leukemia. At the same time, some differences are apparent. For instance, with respect to the parents' perceptions of difficulty, a difference was found between mothers and fathers in terms of their perception of the illness as an additional challenge, with mothers perceiving the illness as a bigger additional challenge than fathers. During the interview, mothers talked generously and freely about their feelings of anxiety, stress and the constant worries regarding illness outcomes combined with the complicated demands of caring for their

child with leukemia. Mothers perceived as very taxing to handle their child's medical condition and the high demands such illness placed on them and the family, referring to the need for much energy and constant awareness along with exceptional skills needed to deal with the situation (i.e., knowledge about the treatments, understanding the child, having the intuition, responding properly to the child's demands, being present constantly), all of which are challenging. Our finding is in agreement with prior studies that demonstrated that mothers experienced a significant level of distress, worries and difficulties from the increased daily demands of parenting in a family with a chronically ill child (Sahler, et al., 2005; Hendricks-Ferguson, 2000; Hoekstra-Weebers, et al., 1999; Knafl & Zoeller, 2000; Seppanen, Kyngas, & Nikkonen, 1999).

Additionally, our data suggest that mothers were more overwhelmed by the ill child's behaviour and the constant struggles with the sibling rivalry than fathers. Guilt, frustration and feeling of being manipulated by the children were most often expressed by mothers. They perceived as particularly challenging to establish a routine in the child's life, to being firm with the child, reinforcing the rules inside the family while also helping siblings to adapt to the changes in the family life including the loss of some parental attention. This finding is consistent with other studies on parents of chronically ill children that found that mothers scored higher on measures of arguments with children and reported greater guilt and frustration than fathers (Knafl & Zoeller, 2000; Rogers & White, 1998).

Yet, despite the mothers' perceptions of difficulties in parenting under such difficult circumstances, our findings also reveal a positive relationship between mothers' perceptions of difficulties and mothers' feelings of competence to deal with the extra

demands placed on them due to a chronically ill child. This finding is consistent with earlier studies that found that mothers often embody a psychological hardiness, characterized by adequate and sustained stamina to perform their parental tasks while handling stressful circumstances (Cox, 1992; Eiser & Havermans, 1992; Elliott-Brown & Barbarin, 1996; Rogers & White, 1998). This may also be related to the mothers' general sense of personal responsibility for all aspects of parenting and family functioning and well being.

On the other hand, our findings indicate that fathers referred more often than mothers to their difficulties in accepting and/or coping emotionally with their child's illness. They experienced a high level of emotional strain and often felt helpless and out of control. During our interview, fathers appeared very open, expressive, and easily able to talk about their feelings of exasperation, doubts about their ability to perform their parental tasks well and often referred to moral, emotional, and physical draining caused by the illness and their powerlessness and their sense of lack of control over their lives. This finding stands in contradiction with prior studies that suggest that the stress of a child's illness is absorbed more by mothers than by fathers, and that the fathers' emotional reactions tend to be kept inside (Brown, 1999; Darke & Goldberg, 1994; Grootenhuis & Last, 1997; Kristjanson & Ashcroft, 1994). Our study suggests that such was not the case for the fathers in this sample.

With respect to the parents' perceptions of competence our findings provide evidence that both mothers and fathers, despite slight variations in their ratings, perceived caring for their ill child as satisfactory and gratifying. Such satisfaction and gratification in parenting fuels the parents' sense of competence, as the themes that emerged from the



interview data suggest, such as the parents' ability to take action, feelings of responsibility, feelings of competence and responsiveness, a sense of managing the parenting suitably, and a belief to be able to adapt to such a challenging and overwhelming situation.

Some parents also referred to the positive impact of their child's illness on themselves and their families. The following themes attest to such positive outcomes: a sense of increased closeness in their families, especially with the children; an increase in their level of expertise in life; a sense of maturity and wisdom; and more appreciation of their lives. This finding is in line with other studies suggesting that despite the negative effects of a childhood cancer in a family, parents also appraise illness experiences as beneficial, constructive and valuable (Clarke-Steffen, 1993; Eiser, et al., 1995; Grootehuis & Last, 1997; Ovenden, 1997). Also, this finding agrees with Bandura's Self-efficacy theory suggesting that experienced difficulties offer opportunities for growth and for turning failures into successes with the effect of improving one's capability to exercise better control over events (Bandura, 1997).

It is possible to speculate that our sample is particularly confident and positive and able to deal with the challenging situation since they have more than one child (except for one couple) and hence, had possibly already established effective parenting routines prior to having a child with leukemia; they were not novice parents. Furthermore, as can be seen from our sample, income level for most of them was rather high and therefore, they did not have to struggle with other issues such as poverty or unemployment that may put them at risk for losing their sense of competence in parenting once facing the situation of a chronically ill child in their family. Our data does not allow

a clear sense of how these factors may be at play, but it suggests that further research needs to address the impact of such factors on the parents' sense of competence, an issue I return to at the end of the chapter. Past studies examining parental satisfaction and competence underline that maturity and socioeconomic status are resources that enhance the performance of the parental roles. Such studies suggest adults who become parents at a more advanced age and parents with more education and income experience more satisfaction from their role as parents (Rogers & White, 1998).

Another important aspect that should also be considered is the parents' perception of their role in their family. Previous research has found significant differences between mothers' and fathers' perceived parental roles in that traditionally, mothers took on the role of primary caregivers for their children, while fathers were primarily involved in providing the financial resources for the family (Larson, Wittrock, & Sandgren, 1994; Mercer & Ritchie, 1997; Van-Dongen-Melman, 1995). Interestingly, our findings reveal no differences between mothers' and fathers' perceptions of their role. It appears that the fathers perceive their role as much as a caregiver as the mothers. When examining more closely, mothers do still refer to themselves as the primary caregivers, whereas fathers perceived their role as supplementing that by helping and supporting the mother, and by being a teacher and guide for their children. This is a very interesting finding that confirms recent parental literature portraying the father's role as being more involved and helpful in family daily routines and as a model for the child's social development and education (Bonney et al., 1999; Hastings & Grusec, 1997; Lamb, 1997, 2000; Lindsay, et al., 1997; Griswold, 1997; Tamis-LeMonda, et al., 2004).

Yet, our findings also suggest that only fathers referred to their role as the financial provider even though the majority of the mothers were also working outside the home. It shows that despite some changes in the perception of parental roles, such new role perceptions remain fragile and are at least at a societal level may not be always accepted.

In sum, although both parents manifested difficulties in coping with the child's illness coupled with a constant sense of uncertainty, positive results also surfaced in terms of the parents' sense of competence. Both parents referred to their abilities to find solutions, resolve problems and acquire knowledge from their parenting experiences. Such a positive shared perspective among parents results in management strategies that further help support the family in positive ways. The presented data also makes quite a convincing case that parents are motivated to act in ways that will lead to a positive self-concept and lead to the improvement of their perceived deficiencies. This result opens a door for recommendations and initiatives regarding the development of different support and educational programs that may help the parents and the families increase their perceptions of efficacy and satisfaction while attempting to fulfill their care-giving responsibilities and meet the needs of the entire family.

### **5.3. Mothers' and Fathers' Orientation towards Uncertainty**

The quantitative results regarding the parents' uncertainty orientation revealed three uncertainty orientation profiles among parents namely; the uncertainty-, the certainty- and the moderate-oriented profile. Among these profiles, there is a tendency for mothers to qualify as moderate-oriented and for fathers as uncertainty-oriented individuals. According to Sorrentino's Uncertainty Orientation theory, uncertainty-oriented individuals have been found to deal with uncertainty by adopting an information seeking behaviour, whereas moderate-oriented individuals behave with an unpredictable and inconsistent way while facing uncertainty (Roney & Sorrentino, 1995a, 1995b; Sorrentino, et al., 1992).

Interestingly, responses to the interview questions reveal different kinds of dimensions of the parents' uncertainty orientation profiles. First and foremost, our findings reveal a mix of coping strategies among all parents. Among these coping strategies, certain are illustrative of the uncertainty-oriented profile such as "talking to others", "asking questions", or "seeking solutions", whereas some others, can be attributed to the certainty-oriented profile such as "living day by day" or "avoid thinking". Given the fact that most parents were found to adopt both confronting and avoidance strategies in an interchangeable manner, the interview analysis leads us to categorize all parents as moderate-oriented if we care to use the profiles at the heart of Sorrentino's theoretical framework. Since the moderate-oriented parents represented the largest group based on Sorrentino's framework, it suggests that there is some validity to using both measures, the scale and the interview, in assessing the parent's manner of dealing with uncertainty. However, the interview appears clearly to better get at the heart

of the parent's sense of uncertainty than Sorrentino's scale that was not necessarily sensitive enough to offer a clear picture, something not surprising since the scale was not developed for this clientele, a point I come back to as I discuss the limits of this study. It supports the idea that a serious childhood illness such as leukemia, leads to continuous ambiguities due to a multitude of factors (i.e., the child's health condition, the evolution of the illness or the efficacy of medical treatments), and hence, many different sources of uncertainty that Sorrentino's measure may not be able to distinguish. Also, the parents' choices of coping strategies to deal with uncertainty vary greatly depending on how uncertainty is perceived at particular moments in time (i.e., as danger or as opportunity). Accordingly, our study suggests that it would be a mistake to assume that parents who are facing an uncertain and life-threatening event are solely represented by the uncertainty or the certainty-oriented profile. Instead, a sense of uncertainty is much more dynamic, situated and context dependent and hence, continuously changes over time.

Also, it should be considered that in Sorrentino's theoretical framework, the concept of uncertainty orientation is studied and understood only through normal personal phases of the life trajectory, and not under such specific detrimental and life-threatening circumstances. Uncertainty orientation is defined as an individual difference dimension that distinguishes among individuals in terms of how they approach new knowledge or avoid ambiguity. Therefore, individuals' coping strategies are constituted along a continuum; at one end of the continuum, are those who perceive uncertainty as a challenge, whereas at the other end are those who try to avoid it. Our interview analyses suggest, however, that parents cope with uncertainty within a more volatile way while facing detrimental and life-threatening events. For instance, it was found that parents

adopted sometimes the “living day by day” or the “avoidance of thinking” strategies, whereas some other times, they coped by “seeking information”. It can be assumed that avoiding thinking about an uncertain situation may reduce the parents’ anxiety and pressure, whereas at some other times, the possibility of finding some new information about ambiguous circumstances can generate feelings of assurance and confidence. Once again, such a finding may be linked to the fact that these parents deal with a life-threatening event, therefore their perceptions of uncertainty is not stable but fluctuates continuously (suggesting also that it is not a personality trait but very much situation dependant, an interaction of personality and context).

With respect to experienced uncertainties, “illness uncertainty” (i.e., illness evolution, efficacy of treatments, illness recurrence and prognosis), “future uncertainty” (i.e., quality of life, child’s developmental outcomes) and “parenting uncertainty” (i.e., disciplining the child, making the right decisions) were all equally noted by both parents. In particular, both parents experienced major uncertainty in terms of their child’s illness and future quality of life, followed by a sense of uncertainty regarding their parenting. This very interesting finding clearly suggests that uncertainty related to illness can also produce other kinds of uncertainty leading to additional stress and constant worry.

Considering parents’ coping with uncertainty, there were no major differences among the parents’ coping strategies mentioned, with the exception of the “avoidance” and the “living day by day” strategies. While mothers more often referred to an avoidance strategy, fathers more often referred to adopting a “living day by day” approach. Our finding disagrees with studies that suggest that young fathers, more than mothers, use different avoidance activities as drugs, alcohol, food, or putting more energy

into work (Sterken, 1996). Such a difference in findings can possibly be explained by the fact that the fathers in our study were more mature in age, well educated and socio-economically advantaged. However, it is very interesting to note that despite the mothers' tendency towards an avoidance behaviour and the fathers' preference to cope on a daily base, it can be argued that the parents still behaved similarly given the fact that both "avoidance" and "living day by day" strategies belong to a general evasive behaviour towards uncertainty. Nevertheless, the evidence that "avoidance" coping was more adopted by mothers may be linked to the fact that the mothers in our study did perceive their role as primary caretakers, despite the fact that most of them worked, and hence, perceived as challenging the new demands of their child's chronic illness in addition to the many regular household tasks and family responsibilities they already had to measure up to (Elliott-Brown & Barbarin, 1996). Both, high levels of stress and uncertainty may be experienced by mothers, hence the "avoidance" strategy can appear as more beneficial possibly protecting them somewhat from the insidious effects of stress on their overall well being. In contrast, the fathers' use of the "living day by day" strategy reflects their philosophy of life that is based on the present, now that they have a child with leukemia. Since the course of the child's illness and its prognosis is uncertain, fathers found it more useful to cope on a daily basis rather planning for the future. At the same time, fathers also referred to active coping strategies such as "talking to others", "asking questions", and "seeking information/solutions", supporting our interpretation that parents do show a very unpredictable behaviour while facing uncertainty.

Another issue that merits consideration is that fathers and mothers adopted, quite equally the "talking to others" strategy. During the interview it was very interesting to see

the fathers' vivid desire to talk about their experiences, their feelings and their emotions to others. This finding goes against rigid sex-roles stereotypes and common beliefs in our society that fathers/males tend to avoid speaking about feelings and that such a coping strategy is primarily invoked by mothers (Grootenhuis & Last, 1997; Sterken, 1996; Larson, et al., 1994; Wintersteen & Rasmussen, 1997). It is also important to underline that the parents had a positive outlook in terms of the future. Such has also be found in other studies and suggests that such as parents' positive perceptions will improve their coping methods when faced with challenging and life-threatening circumstances (Beresford, 1994).

An additional issue to consider is the possible influence that parents have on each other regarding their uncertainty orientation. Of interest is the finding of a similar uncertainty orientation profile among most couples. The fact that no opposite uncertainty-orientation profile was found among couples allows for the conjecture that parents may influence each other in terms of perceptions and appraisals of uncertainty as well as their coping with uncertainty (Beresford, 1994). It can be assumed that a possible coexistence of different uncertainty-orientation profiles within a parental couple would probably impede pleasant and cooperative parenting. Nevertheless, this finding cannot be generalized given the small sample size. A future study should be conducted to explore the couples' uncertainty orientation, a study with a larger and more diverse sample of parents.

In addition, it is noteworthy to remark that we found a significant positive relationship between the parents' uncertainty orientation and their sense of competence when comparing the quantitative measures. As shown, uncertainty-oriented parents



scored high in their perception of efficacy and low in satisfaction, whereas certainty-oriented parents revealed a high score in their perception of satisfaction yet were low in efficacy. Therefore, it can be assumed that uncertainty-oriented individuals try to resolve uncertainty and exhibit a very active coping behavior and may perceive themselves as very efficacious. Conversely, certainty-oriented people prefer the familiar, ignore changes, avoid uncertainty, and experience more satisfaction by relying on what they know and do. However, more qualitative research is needed to further explore the relationship between parents' coping with uncertainty and their orientation towards uncertainty, as well as the relation between the parents' perception of competence and their uncertainty orientation over time and among larger samples.

In sum, from the analysis of the parents' perceptions of uncertainty, strategies of coping with uncertainty and their perceptions of the future, an understanding about their orientation towards uncertainty was gained. As suggested by our study, parents behave in a very inconsistent and volatile way while facing uncertainty and could profit from some educational and support programs that directly address such fluctuations in ways of coping. Accordingly, prior studies demonstrated that a person's uncertainty orientation is an important predictor regarding an individual's coping behaviour to manage uncertainty (Forgas, Williams Kipling, & Wheeler, 2001). Hence, it can be concluded that knowing and understanding the parents' orientation towards uncertainty within a life-threatening context may help health care professionals develop parental education and support programs that are personalized according to an individual's uncertainty orientation profile.

#### **5.4. Limitations of the study**

Certain limitations to the study need to be outlined. First, caution should be exercised with regards to the results as this project relied on a very small and convenience sample and hence non representative of society at large. Both differences and similarities among parental characteristics are not meant to be generalizable but instead, to offer some insights into the parents' sense of competence and the manner they deal with uncertainty. Furthermore, the parents in this sample are quite diverse in terms of their ethnicity and original cultural background, yet again, given the small sample size, such differences could not be taken into consideration in a consistent fashion. Instead, further research should address in particular how such variables further influence the parents' sense of competence and their ways of dealing with uncertainty.

Our results were drawn from parents in middle age, well educated, married, socio-economically advantaged and experienced in parenting given the fact that they had more than one child in family (except one couple). Accordingly, our findings can only be descriptive of this group of parents that appeared to manage well with their child's chronic illness given such resources. Yet, parents who face other challenges in life such as poverty, unemployment and issues related to lack of social inclusion may experience the illness of a child in their family as yet more challenging and very different. More research is needed to examine the manner with such factors influence the parents' adaptation and management under such difficult circumstances.

Second, the Parenting Sense of Competence Scale (PSOC) used in this study, was not designed to measure the parents' perceptions of efficacy and satisfaction while

dealing with a life-threatening illness in the family. Hence, the measure may not be applicable to such a sample and not sensitive enough to underline dimensions of parenting particularly challenging under such circumstances. At the same time, the participating parents were asked to think about parenting now in their family that is facing the challenges of a child diagnosed with leukemia while completing the questionnaire. Yet, many factors beyond control in this study could have influenced their manner of responding. For instance, it should be kept in mind that the child's stage of treatment may influence parental perceptions of competence. Furthermore, the questionnaire only captures data at one point in time. Therefore, it was not possible to examine the parenting experience over the whole remission phase. It is important to remind researchers that empirical work to date has certain limits regarding the assessment of parents' sense of competence in life-threatening situations, since studies do not control in a systematic manner for the stage of the child's illness. Furthermore, no measure exists specifically targeting this population. Instead, in all studies reviewed and in our study, questionnaires used with the general population had to be employed; these questionnaires maybe not actually able to disentangle the many dimensions that contribute to the parents' sense of competence that appears to change continuously.

Third, the Uncertainty Orientation measures (Sorrentino, et al., 1992; Sorrentino et al., 2001), designed to assess individual differences on large samples of students or non academic people, have never been used to appraise parents' orientation towards uncertainty while parenting a chronically ill child. Given that this study applied the Uncertainty Orientation measures, the results of the present study should be regarded as preliminary. Furthermore, since there were no longitudinal data, it was not possible to

explore if the parents' orientation towards uncertainty changes over the child's convalescence period. It would have been interesting to adopt a repeated measure design. Yet, such a methodological approach was well beyond the scope of this study.

Fourth, our analysis focused on identifying themes among parents in terms of their sense of competence and ways of dealing with uncertainty. Yet, it would also be interesting to pursue a more detailed case analysis of individual parents and explore the manner they responded to the questions. This would help us understand better whether parents who perceive themselves as competent are also the ones who less challenged by uncertainty. Furthermore, it would be interesting to explore how the ill-children's siblings felt about the new family situation. Accordingly, rich detailed family case studies could also be promising in offering insights into ways to better support families when facing such challenging situations.

## **5.5. Implications**

Overall, the present study contributes to an understanding of mothers' and fathers' experiences of parenting a child with leukemia, and offers some insights into ways to enhance the parents' perceptions of competence and to improve their ability to manage uncertainty. The study suggests the potential for both parents to experience dissatisfaction with their parenting due to the illness which may be perceived as an additional challenge given the experienced uncertainties. Moreover, the results suggest that acquiring information about a parents' coping may be useful and can help professionals develop support and educational programs for parents.

There is some literature on parental education, that has proposed family-centered programs aimed at supporting parents to deal with the chronic illness of their child (Wenninger, et al., 2000). For instance, the Berlin parental education program entailed a comprehensive family-oriented management of a common childhood chronic disease, (i.e., atopic dermatitis, Wenninger, et al., 2000). It helps improve mothers' and fathers' self-management skills and has been found to positively impact the course of the disease as well as the family's quality of life. The Berlin parental education program, based on Social Learning theory, centers on the parents performance of new behaviours, and their self-efficacy beliefs treating them as important cognitive mediators in health behaviour. It was found that the majority of parents reported that their confidence in managing their child's chronic illness increased through participation in the program. Furthermore, specific programs have also been developed to provide information, problem-solving education, development of communication skills, ability on need assessment and available resources to family members and health care professionals responsible for

physical and psychosocial care of a person with a cancer diagnosis (Bucher & Houts, 1999; Masera, et al., 1997; Pickett, Barg, & Lynch, 2001; Grahn & Johnson, 1990; Wilkinson, Bailey, Aldridge, & Roberts, 1999). Another example, the home-based Family Caregiver Cancer Education Program was designed for family caregivers and addresses the major informational areas that individuals need in order to care for a loved one who is living with cancer at home (Pickett, et al., 2001).

Yet, our study demonstrated that childhood cancer does not affect families in the same way. Therefore, it is logical to assume that the type of intervention for each family must also be attuned to the nature and the seriousness of the problem and to the level of adjustment of each parent and family member. Our results revealed that in parents of children surviving cancer, uncertainty is one of the main problems influencing the family's functioning and the parents' sense of competence. From our data, it was also demonstrated that the parents' orientation and coping with uncertainty vary because they are likely to encounter diverse experiences and face different family's demands over the course of their child's illness. It suggests that dealing with uncertainty that arises from such a life-threatening circumstance leads to volatile coping, depending also on how the individual perceives a particular uncertainty at a particular time. Consequently, in order to support these parents to cope suitably with different uncertainty issues, the findings from this study suggests that a prior identification of the parents' orientation towards uncertainty could be very promising and crucial for intervention that is then truly supportive of these parents. Such an identification will provide important information about the parents' preferences in terms of resolving or avoiding uncertainty when it is

experienced, and will also help professionals to create more tailored and personalized approaches that respect the parents' diversities.

Given the fact that people learn what they need to know to make the world work for them, a plausible educational approach may consist of identifying the kinds of knowledge that parents need to regulate their actions suitably and to master their experienced uncertainties. Earlier studies pointed to evidence that uncertainty-oriented individuals are more open to change and likely to embrace the unfamiliar, whereas certainty-oriented people prefer stability and adherence to the known and familiar (Sorrentino & Roney, 1999, 2000). People that behave in an unpredictable and volatile way in their coping with uncertainty, the so called moderate-oriented, adopted coping strategies that are typical to both uncertainty and certainty-oriented individuals. Hence, recognising the tremendous importance yet also variation of the parents' uncertainty orientation, educational programs should take them into consideration by developing specific intervention programs designed to encourage suitable motivational dispositions and cognitive skills. Research suggests that through quality education programs, people are able to develop cognitive capabilities such as enhanced logical thinking, open-mindedness, problem solving, together with motivation such as self-efficacy and orientation towards hard work that may prove valuable to them in dealing with difficult life situations (Ross & Mirowsky 1999). The process of learning builds upon skills and confidence in problem solving, which may allow parents to confront new issues with a heightened sense of personal control.

From the summary of our results in terms of late consequences of childhood cancer for the whole family, it was concluded that parental education programs should

aim to improve the quality of survival of the child and its family and focus on the following: a) increasing parents' confidence and satisfaction, b) improving parents' knowledge, understanding, and skills regarding child-rearing, c) mastering uncertainty and d) improving social support networks among parents. It can be assumed that any educational intervention that improves parents' sense of competence and ability to master uncertainty under life-threatening conditions may in turn increase the likelihood that parents will perceive their child's development as less complicated (Coleman & Karraker, 1997; Thomas, 1996). It also suggested that personalized interventions that respond to each family members' needs can facilitate the family's adaptation, improve the couple's communication and enhance mutual support among family members.

It is important to mention that parental education programs can be employed by different health care professionals (i.e., family nurses, social workers, educators) who support parents during the child's recovery and who are able to assess parents' needs according to specific conditions. These programs may include home-based interventions or workshops with different educational activities for both parents and siblings, in order to enhance their ability to work together and better cope with the issues most commonly encountered in parenting their child with leukemia.

With respect to parental support, the creation of workshops that respond to different kinds of parents with particular concerns and problems, should most importantly encourage small groups to work together within a positive, collaborative and interactive environment in which parents feel comfortable and safe to talk about their challenges (Mandel, 2003). Such workshops would allow parents to develop a network with other parents in similar situations, to be actively involved and to discuss with others, to share



their personal experiences, to offer practical solutions to real problems, and to gain more knowledge and expertise, which in turn may enhance their perceptions of competence (Mandel, 2003; Padberg & Padberg, 1990; Sharan, 1990).

A number of educational techniques can also be suggested such as: didactic instruction, modeling (i.e., appreciate or validate a parent's personal experience); supervising a parent's relevant behaviours, promoting problem-solving; practicing of skills in structured clinical settings as well as at home, role-play and positive reinforcement (i.e., providing encouragement) in order to solidify behavioural and cognitive changes offered by the educator or from other parents during group discussions. Our findings support evidence for the inclusion of these educational methods through different workshops designed for both parents together given the fact that most similarities than differences were found among parents in terms of their coping with such a challenging and uncertain situation..

Yet, our findings revealed that parents, especially mothers, experienced additional challenges and uncertainties regarding their parenting in terms of discipline and daily interactions with their children. For instance, organizing regular workshops, especially for mothers, that address issues with respect to the parenting style now that the situation in the family is totally different and more challenging may be very beneficial for these mothers. The aim of such a workshop is to instruct mothers in how to effectively respond to and communicate with their children as well as to attend to and reward appropriate behaviour while ignoring maladaptive behaviour.

In addition, this research project sheds light on the numerous stressors and significant challenges that fathers face while parenting a chronically ill child. Therefore,

educational workshops should be aimed at increasing fathers' perceptions of competence and mastery of uncertainty. Given the fact that our findings revealed the fathers' openness and tendency to talk to others about their feelings and experiences, this support evidence that workshops, specifically for fathers, would allow them to come together to share their emotions and feelings, and to discuss different aspects of fatherhood.

Moreover, the impact that the child's chronic condition has on the other family members should be explored. Our analysis suggests that parents felt challenged not only by the illness per se, but in particular the manner the illness complicated sibling rivalry. Hence, educational programs should consider siblings as well. It could be interesting to create workshops for siblings with the aim to help them better adapt to these family changes and new routines which in turn, may enhance parents' ability to properly discipline their children. Formal education programs that use play and discussion to explain to siblings what cancer is, its routine treatment procedures, and to give reassurance that their feelings of anger and jealousy are common and normal, could be very helpful and constructive. A further benefit may consist of the opportunity for siblings to learn to develop greater empathy and sensitivity towards the child with leukemia and their parents' needs, as well as to develop of coping strategies to face such a challenging situation. They could learn more about their role in the family, now that one of their brothers or sisters is ill.

There is an extensive literature on the construct of uncertainty (Berger & Calabrese, 1975; Burszajn, et al., 1990; Sedikides & Strube, 1997; Sorrentino, et al., 1992). Hence, uncertainty is one of the most universal characteristics that can influence the social mind, the individual's cognitions, beliefs and motivation. The way individuals

deal with uncertainty has a major impact on their coping behaviour. Therefore, it is important to assess an individual's orientation towards uncertainty to better guide and support a person in managing uncertainty through both clinical practice and educational programs. Given the above, the present study suggests that it could be interesting to determine whether other existing Uncertainty Orientation measures, other than the one used here, could be applied to assess parents' uncertainty orientation when dealing with a chronic illness in their family and what implications that may have for intervention.

## **5.6. Recommendations**

The process of parenting a child with leukemia is an area of research that certainly warrants further study. The more that is discovered about the parents' sense of competence in terms of efficacy and satisfaction within a stressful context, the more assistance, guidance and education can be provided to both parents and eventually, the larger family system. The results of the current study may contribute greatly to the literature on parenting and parent education. There is a lack of knowledge about the parents' uncertainty orientation and perception of competence when parenting a child with leukemia. The assessment of the parents' uncertainty orientation under life-threatening circumstance is a topic that has not received much research attention. Knowing the parent's personal orientation towards uncertainty may lead professionals to develop an educational and proactive program designed to help parents manage uncertainty better. Future researchers should be encouraged to employ the Uncertainty Orientation measures in the parents' assessment in order to offer more pointed intervention and support.

Although much research by Sorrentino and colleagues exists on behaviour of the uncertainty- and certainty-oriented individuals, there is little knowledge about moderate-oriented people. The present study has provided information about the moderate-oriented profile. Future studies focusing on individual differences in uncertainty orientation within the context of a chronic illness should further consider the possibility for individuals to behave in an unpredictable and volatile manner while coping with uncertain and life-threatening circumstances.

There are also other areas worth exploring further such as the variability in uncertainty experiences and meanings, the functions of appraisal and emotion in uncertainty management, the variety of parental coping behaviour to uncertain critical circumstances and the relationship between parents' perceptions of competence and handling uncertainty. Moreover, dilemmas of social support and education in managing uncertainty may arise from difficulty coordinating the goals of parents (i.e., one partner might focus on reducing uncertainty while the other focuses on increasing or sustaining uncertainty).

The empirical results of the present study suggest directions for additional investigations on parents dispositional uncertainty over time and partners' reciprocal influence managing uncertainty, pointing to the need for longitudinal studies. In addition, follow-up studies to the current one should focus on identifying possible changes in parents' uncertainty orientation throughout the course of their child's illness. Similarly, the study calls for extensive longitudinal research to investigate parents' possible changes of their perception of competence in terms of efficacy and satisfaction throughout the evolution of their child's illness. There is not enough knowledge about the stability or changes of parents' perception of competence over time while facing the course of their child's chronic illness. Further research needs to be conducted on a larger sample of parents within the same, but possibly also a different illness context of similar magnitude (i.e., other serious chronic child illnesses).

Future research should also focus more on fathers' concerns and demands within the context of a family dealing with a chronic illness. According to the literature, past studies of children with special needs focused primarily on mothers, whereas fathers were

often not considered or were treated by professionals as relatively unimportant in terms of the developmental outcomes of a special needs child (Dahlquist, et al., 1996; Dollahite, 2004; Kochanska, et al., 1997; Lamb & Laumann-Billings, 1997; Olson, Dollahite, & White, 2002). In view of this evidence, the needs, concerns and experiences of fathers should be studied in greater detail and without falling into the trap of societal stereotypes and beliefs about males. Future extensive research on fathers' perceptions of competence and roles while dealing with a chronically ill child may provide more insights into today's fathering. This could possibly help professionals to better attend to the fathers' needs and requests when parenting under life-threatening conditions and promoting an overall positive family adaptation.

In sum, research should continue to focus on the experience and meaning of uncertainty in families struggling with a child that is chronically ill, the assessment of uncertainty, and subsequent interventions and support programs aimed at supporting parents in such challenging situations. The application of uncertainty management techniques for educational purposes should also be investigated further. Hence, understanding the nature and kinds of uncertainty enhances the professional's ability to describe and explain its influence on coping behaviour and on the individual's perception of competence allowing for the development of strategies for improving the parents' lives and for maintaining some sense of normality in their family life.

Not at last, more research needs to focus on the family as a whole, and in particular the problems siblings face in such situations. How the parents and the siblings themselves may cope with jealousy and challenges due to illness needs to be further

investigated as it may inform intervention and support programs that support the well being of all family members.

## **5.7. Conclusion**

Childhood cancer constitutes a crucial crisis both emotionally and practically for the child and its family. A specific and highly stressed small sample of parents with a 4 to 12 year old child with leukemia were chosen for the purpose of the study. This study was conducted in order to explore and determine mothers' and fathers' orientation towards uncertainty and their perception of competence. Insights then led to propositions of intervention and support programs that may support the well being of such families and all its members.

Although several studies on childhood cancer have extensively examined the impact of such an illness on the child and the family in terms of coping and adjustment, little is known about the parents' orientation towards uncertainty and their perceptions of competence. Very few studies on parenting self-efficacy have considered the impact of parental perceptions of uncertainty and parents' self-efficacy beliefs (Allen, 1993).

The current study succeeded in illustrating and describing parents' perceptions of competence, uncertainty orientation and behavioural responses within the context of a child's chronic illness. Furthermore, the relationship between mothers' and fathers' perceptions of competence and their orientation towards uncertainty in parenting a child with leukemia were examined.

On the one hand, it is noteworthy to mention that in this study, Uncertainty Orientation theory served as a guide to explore and describe the parents' uncertainty orientation. It was the first time that Uncertainty Orientation theory was applied in the context of dealing with a chronic and life-threatening illness in a family and as experienced by a child in that family. Most importantly, past studies inspired by the



Uncertainty Orientation theory have not considered the moderated-oriented individuals. Yet, our findings suggest the prevalence of the moderate-oriented profile among parents who struggle with a child having been diagnosed with leukemia. Our study suggests further that awareness of the existence of different uncertainty orientation profiles and behaviours towards uncertainty may allow health care professionals and educators to tailor interventions to individual needs, making them more personal and possibly more effective.

Our study also suggests that the parents' sense of competence in terms of efficacy and satisfaction is fundamental to and may provide a clearer understanding of parenting behaviour. The study underlined both parents' perceptions of difficulty in dealing with their child's illness, the parents' ability to manage and respond to different family demands with a positive attitude, and the parents' perceptions about the future. Yet, further investigations to better understand parenting issues that trigger parents' perceptions of efficacy and satisfaction may be worthwhile, given their influence on parenting and the well-being of the family.

With respect to the relationship between uncertainty orientation and sense of competence, the study also demonstrates that uncertainty-oriented parents exhibit a high level of efficacy, whereas certainty-oriented parents manifested a high level of satisfaction. This finding suggests that the relationship between one's perception of competence and uncertainty orientation needs to be considered in intervention and education programs. Hence, to provide sustained help and support, each individual must be correctly evaluated in terms of their needs and concerns and the dimensions examined in this study.

Given the fact that parent education is based on the assumption that parenting is a learned behaviour (Bandura, 1989; Schneewind, 1995), parent education may offer opportunities to parents with a child with special needs, to learn and acquire further competence and skills that will enhance their perceptions of feeling good and feeling effective as a parent. Although there are already some parenting education programs about childhood cancer dealing with its implications and coping strategies, these programs target parents without any concern for their individual differences in terms of their uncertainty orientation and sense of parenting competence. The challenge for the education system resides in establishing more personalized parental education programs that are based on an accurate prior assessment of the parents' orientation towards uncertainty and perceived competence. Clinicians and educators will find the study useful as it implies that parents' perceptions of uncertainty and sense of competence need to be assessed in order to provide tailor made educational programs to assist them throughout the illness of their child. Through an individual based intervention program, parents may experience more joy and fewer frustrations in their parenting, resulting in a harmonious parent-child relationship, which in turn may have significant implications for the social and psychological development of the child and its siblings, as well as whole family.

The benefit of such a targeted education also has implications for the community at large, as it may result in creating more independent and self-confident individuals who cope effectively with their child's chronic illness. Parents can maintain a normal lifestyle and eventually remain active and productive members of society.

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**APPENDICES**

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*Appendix I***CONSENT FORM**

**Research study :** Parenting a Child with Leukemia: Mothers' and Fathers' Sense of Competence and Orientation towards Uncertainty

**Researcher:** Konstantina Fyta  
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**Professor:** Mme Irene Rahm, PhD  
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Dear parent,

You are invited to participate in a research study entitled "Parenting a Child with Leukemia: Mothers' and Fathers' Sense of Competence and Orientation towards Uncertainty".

The purpose of this study is to explore and describe the uncertainty parents face and their sense of competence in day-to-day experiences parenting their children with leukemia after their return home.

If you desire to collaborate in this project, you will be asked to complete three questionnaires and a 45 minutes interview. During the interview, you will be asked questions about your feelings concerning perceptions of competence and experiencing



uncertainty regarding parenting your ill child. I would like to specify that the interview, if you consent, will be recorded. The interview will occur at a time that is mutually convenient. In answering the interview questions, you will be asked for your opinions. There are no wrong or right answers. You also may choose not to answer certain questions.

Please be reassured that every effort is made to prevent any feeling of discomfort throughout your participation. You may find the experience beneficial as you will have the opportunity to share your thoughts on being a parent to a chronically ill child. It is important to add however, that we offer no payment for your participation. In spite of this, it is expected that your participation will facilitate the experience of future parents of chronically ill children, by helping health care professionals and other specialists to better understand your experience, feelings and concerns.

You are encouraged to ask relevant questions at any time during the study and you are free to withdraw at any time should you wish. Your decision to participate or not to participate in the study will have no influence whatsoever on your child's care.

Please note that your answers to the interview questions will remain confidential and will be seen only by the investigator and her research committee. All responses remain anonymous and will be identified simply with a subject number. When the written report is completed, no names will be used. The findings of this research study may be published in academic journals. This research study is approved by the Human Subjects Ethical Review Committee of the "Université de Montréal".

"I have read carefully the above consent form. The nature, demands, risks and benefits of the research study have been explained to me. I understand that I may withdraw from the project at any time without any consequence for me or my child. A copy of this consent form can be made available to me upon request."

**Participant's Signature**

**Date**

**Researcher's Signature**

**Date**

*Appendix II*

Family No.		M		F		Date	
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**The Demographic Questionnaire**

<b>1. Parent</b>			
Mother	<input type="checkbox"/>	Father	<input type="checkbox"/>
<b>2. Name</b>			
First name	<input type="text"/>	Last name	<input type="text"/>
<b>3. Address</b>			
Street	<input type="text"/>		
Area	<input type="text"/>	Zip Code	<input type="text"/>
City	<input type="text"/>		
<b>4. Telephone</b>			
Home	<input type="text"/>	Work	<input type="text"/>
Cell-phone	<input type="text"/>		
<b>5. Citizenship</b>			
	<input type="text"/>		
<b>6. Country of origin</b>			
Quebec	<input type="checkbox"/>	Canada	<input type="checkbox"/>
Other Country	<input type="text"/>		
<b>7. Age</b>			
20-24	<input type="checkbox"/>	35-39	<input type="checkbox"/>
25-29	<input type="checkbox"/>	40-45	<input type="checkbox"/>
30-34	<input type="checkbox"/>	45-49	<input type="checkbox"/>

<b>8. Education</b>			
High School	<input type="checkbox"/>	Undergraduate Degree	<input type="checkbox"/>
Post Secondary	<input type="checkbox"/>	Postgraduate Degree	<input type="checkbox"/>
College/Diploma	<input type="checkbox"/>		

<b>9. Occupation</b>			
Professional	<input type="checkbox"/>	Cleric	<input type="checkbox"/>
Labourer	<input type="checkbox"/>	Owner/Manager	<input type="checkbox"/>
Other (please specify)	<input type="text"/>		

<b>10. Occupational status</b>			
Employed	<input type="checkbox"/>	Welfare	<input type="checkbox"/>
Unemployed	<input type="checkbox"/>		
Other (please specify)	<input type="text"/>		

<b>11. Household Annual Income</b>			
\$0-39,000	<input type="checkbox"/>	\$120,000-139,000	<input type="checkbox"/>
\$40,000-59,000	<input type="checkbox"/>	\$140,000-159,000	<input type="checkbox"/>
\$60,000-79,000	<input type="checkbox"/>	\$160,000-179,000	<input type="checkbox"/>
\$80,000-99,000	<input type="checkbox"/>	More than \$180,000	<input type="checkbox"/>
\$100,000-119,000	<input type="checkbox"/>		

<b>12. Children</b>			
Number of Boys	<input type="checkbox"/>	Number of Girls	<input type="checkbox"/>

## *Appendix III*

### **The Interview Questions**

Q1. Would you like to describe to me some of the joys and pleasures of parenting?

Q2. Could you talk to me about some of the challenges of parenting?

Q3. Could you describe to me your parenting in this moment that you have a child with leukemia?

Q4. How do you perceive your role as a mother/father in this particular situation?

Q5. Is there something particularly challenging to you as a mother/father of a chronically ill child?

Q6. Are there issues with respect to parenting, now with an ill child, that remain ambiguous or confusing to you?

Q7. When you feel ambiguity or confusion, how do you cope with such feelings?

Q8. Would you like to talk to me about your life in the future? How do you think of the future? Will your parenting become easier or more challenging? What are some of the things you are afraid of as a parent?

Q9. If you think of all that happened to you as a parent since your child's diagnosis what kind of support and advice would be the most helpful for other parents who find themselves in your situation?

## *Appendix IV*

### **The Parenting Sense of Competence Scale [(PSOC), Johnston & Mash, 1989]**

Being A Parent (mother)

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Listed below are a number of statements. Please respond to each item, indicating your agreement or disagreement with each statement in the following manner.

If you strongly agree, circle the letters SA

If you agree, circle the letter A

If you mildly agree, circle the letters MA

If you mildly disagree, circle the letter D

If you strongly disagree, circle the letters SD

- |     |  |                 |
|-----|--|-----------------|
| 1.  | The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired. | SA A MA MD D SD |
| 2.  | Even though being a parent could be rewarding, I am frustrated now while my child is at his/her present age                                  | SA A MA MD D SD |
| 3.  | I go to bed the same way I wake up in the morning – feeling I have not accomplished a whole lot.   | SA A MA MD D SD |
| 4.  | I do not know what it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated.                      | SA A MA MD D SD |
| 5.  | My mother was better prepared to be a good mother than I am.   | SA A MA MD D SD |
| 6.  | I would make a fine model for a new mother to follow in order to learn what he would need to know in order to be a good parent.              | SA A MA MD D SD |
| 7.  | Being a parent is manageable, and any problems are easily solved.  | SA A MA MD D SD |
| 8.  | A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one.   | SA A MA MD D SD |
| 9.  | Sometimes I feel like I'm not getting anything done.   | SA A MA MD D SD |
| 10. | I meet my own personal expectations for expertise in caring for my child.  | SA A MA MD D SD |
| 11. | If anyone can find the answer to what is troubling my child, I am the one.   | SA A MA MD D SD |
| 12. | My talents and interests are in other areas, not in being a parent.  | SA A MA MD D SD |
| 13. | Considering how long I've been a mother, I feel  | SA A MA MD D SD |

thoroughly familiar with this role.

- |   |                 |
|---|-----------------|
| 14. If being a mother of a child were only more interesting, I would be motivated to do a better job as a parent. | SA A MA MD D SD |
| 15. I honestly believe I have all the skills necessary to be a good mother to my child                            | SA A MA MD D SD |
| 16. Being a parent makes me tense and anxious   | SA A MA MD D SD |



**The Parenting Sense of Competence Scale [(PSOC), Johnston & Mash, 1989]**

Being A Parent (father)

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Listed below are a number of statements. Please respond to each item, indicating your agreement or disagreement with each statement in the following manner.

If you strongly agree, circle the letters SA

If you agree, circle the letter A

If you mildly agree, circle the letters MA

If you mildly disagree, circle the letter D

If you strongly disagree, circle the letters SD

- |   |                 |
|---|-----------------|
| 1. The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired. | SA A MA MD D SD |
| 2. Even though being a parent could be rewarding, I am frustrated now while my child is at his/her present age                                  | SA A MA MD D SD |
| 3. I go to bed the same way I wake up in the morning – feeling I have not accomplished a whole lot.   | SA A MA MD D SD |
| 4. I do not know what it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated.                      | SA A MA MD D SD |
| 5. My father was better prepared to be a good mother than I am.   | SA A MA MD D SD |
| 6. I would make a fine model for a new father to follow in order to learn what he would need to know in order to be a good parent.              | SA A MA MD D SD |
| 7. Being a parent is manageable, and any problems are easily solved.  | SA A MA MD D SD |
| 8. A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one.   | SA A MA MD D SD |
| 9. Sometimes I feel like I'm not getting anything done.   | SA A MA MD D SD |
| 10. I meet my own personal expectations for expertise in caring for my child.   | SA A MA MD D SD |
| 11. If anyone can find the answer to what is troubling my child, I am the one.  | SA A MA MD D SD |
| 12. My talents and interests are in other areas, not in being a parent.   | SA A MA MD D SD |
| 13. Considering how long I've been a father, I feel thoroughly familiar with this role.   | SA A MA MD D SD |
| 14. If being a father of a child were only more interesting,  | SA A MA MD D SD |

I would be motivated to do a better job as a parent.

15. I honestly believe I have all the skills necessary to be a good father to my child SA A MA MD D SD
16. Being a parent makes me tense and anxious SA A MA MD D SD

**Scoring Instructions for the Parenting Sense of Competence Scale**  
 [(PSOC; Johnston & Mash, 1989)]

**Satisfaction Scale**

Items 2, 3, 4, 5, 8, 9, 12, 14, and 16

Disagreeing indicates greater satisfaction so:

SD = 6, D = 5, MD = 4, MA = 3, A = 2, SA = 1

2 (frustrated)	==
3 (not accomplished)	—
4 (feel manipulated)	—
5 (mother/father better prepared)	—
8 (don't know if good)	—
9 (not getting done)	—
12 (talents elsewhere)	—
14 (better if interested)	—
16 (tense)	—
Satisfaction Total	—

**Efficacy Scale**

Items 1, 6, 7, 10, 11, 13, and 15

Agreeing indicates greater efficacy so:

SA = 6, A = 5, MA = 4, MD = 3, D = 2, SD = 1

1 (problems easy)	==
6 (fine model)	—
7 (manageable)	—
10 (meet expectations)	—
11 (I can find answer)	—
13 (familiar with role)	—
15 (have skills)	—
Efficacy Total	—

PSOC Total —  
 (Satisfaction + Efficacy)

*Appendix V*

**QUESTIONNAIRE ONE**

**A PROJECTIVE TEST**

*Participant's Number:*

## **SENTENCE INTERPRETATIONS**

### **Instructions**

You are going to see a series of sentences, and your task is to tell a story that is suggested to you by each sentence. Try to imagine what is going on. Then tell what the situation is, what led up to the situation, what the people are thinking and feeling, and what they will do. In other words, write as complete a story as you can, a story with plot and characters.

You will have twenty (20) seconds to look at a sentence and then four (4) minutes to write your story about it. Write your first impressions and work rapidly. I will keep time and tell you when it is time to finish your story and to get ready for the next sentence. There are no right or wrong stories or kinds of stories, so you may feel free to write whatever story is suggested to you when you look at a sentence. Spelling, punctuation, and grammar are not important. What is important is to write out as fully and as quickly as possible the story that comes into your mind as you imagine what is going on. Notice that there is one page for writing each story. If you need more space for writing any story, use the reverse side of the paper.

1. **TWO PEOPLE ARE WORKING IN A LABORATORY ON A PIECE OF EQUIPMENT.**

*Sentence Number* \_\_\_\_\_

*Participant's Number*

1. What is happening? Who is (are) the person(s)?

2. What has led up to this situation? That is, what has happened in the past?

3. What is being thought? What is wanted? By whom?

4. What will happen? What will be done?

2. **A PERSON IS SITTING, WONDERING ABOUT WHAT MAY HAPPEN.**



*Sentence Number* \_\_\_\_\_

*Participant's Number*

1. What is happening? Who is (are) the person(s)?

2. What has led up to this situation? That is, what has happened in the past?

3. What is being thought? What is wanted? By whom?

4. What will happen? What will be done?

3. **A YOUNG PERSON IS STANDING: SOME KIND OF OPERATION CAN BE SEEN IN THE BACKGROUND.**

*Sentence Number* \_\_\_\_\_

*Participant's Number*

1. What is happening? Who is (are) the person(s)?

2. What has led up to this situation? That is, what has happened in the past?

3. What is being thought? What is wanted? By whom?

4. What will happen? What will be done?

4. **A PERSON IS THINKING: AN IMAGE OF A CROSSROADS IS IN THE PERSON'S MIND.**

*Sentence Number* \_\_\_\_\_

*Participant's Number*

1. What is happening? Who is (are) the person(s)?

2. What has led up to this situation? That is, what has happened in the past?

3. What is being thought? What is wanted? By whom?

4. What will happen? What will be done?

**QUESTIONNAIRE TWO**

**A PERSONAL OPINION QUESTIONNAIRE**

### Instructions

The following is a study of what the general public thinks and feels about a number of important social and personal questions. The best answer to each statement below is your personal opinion. We have tried to cover many different and opposing points of view; you may find yourself agreeing strongly with some of the statements, disagreeing just as strongly with others, and perhaps uncertain about others; whether you agree or disagree with any statement, you can be sure that many people feel the same as you do.

Circle +3, +2, +1, or -1, -2, -3, depending on how you feel in each case.

+1: I AGREE A LITTLE

-1: I DISAGREE A LITTLE

+2: I AGREE SOMEWHAT

-2: I DISAGREE SOMEWHAT

+3: I AGREE VERY MUCH

-3: I DISAGREE VERY MUCH

1. There is hardly anything lower than a person who does not feel a great love, gratitude and respect for his or her parents.

+3    +2    +1    -1    -2    -3

2. An insult to our honor should always be punished.

+3    +2    +1    -1    -2    -3

3. Books and movies ought not to deal so much with the unpleasant and seamy side of life; they ought to concentrate on themes that are entertaining or uplifting.

+3    +2    +1    -1    -2    -3

4. What the youth needs most is strict discipline, rugged determination, and the will to work and fight for family and country.

+3    +2    +1    -1    -2    -3

5. No sane, normal, decent person could ever think of hurting a close friend or relative.

+3    +2    +1    -1    -2    -3

6. Young people sometimes get rebellious ideas, but as they grow up they ought to get over them and settle down.

+3    +2    +1    -1    -2    -3

7. The findings of science may someday show that many of our most cherished beliefs are wrong.

+3 +2 +1 -1 -2 -3

8. People ought to pay more attention to new ideas, even if they seem to go against the Canadian way of life.

+3 +2 +1 -1 -2 -3

9. If people would talk less and work more everybody would be better off.

+3 +2 +1 -1 -2 -3

10. A person who has bad manners, habits, and breeding can hardly expect to get along with decent people.

+3 +2 +1 -1 -2 -3

11. Insults to our honor are not always important enough to bother about.

+3 +2 +1 -1 -2 -3

12. It is right for people to raise questions about even the most sacred matters.

+3 +2 +1 -1 -2 -3

13. Obedience and respect for authority are the most important virtues children should learn.

+3 +2 +1 -1 -2 -3

14. There is no reason to punish any crime with the death penalty.

+3 +2 +1 -1 -2 -3

15. Anyone who would interpret the Bible literally just doesn't know much about geology, biology, or history.

+3 +2 +1 -1 -2 -3

16. In this scientific age the need for a religious belief is more important than ever before.

+3 +2 +1 -1 -2 -3

17. When they are little, kids sometimes think about doing harm to one or both of their parents.



+3 +2 +1 -1 -2 -3

18. It is possible that creatures on other planets have founded a better society than ours.

+3 +2 +1 -1 -2 -3

19. The prisoners in our corrective institutions, regardless of the nature of their crimes should be treated humanely.

+3 +2 +1 -1 -2 -3

20. The sooner people realize that we must get rid of all traitors in the government, the better off we'll be.

+3 +2 +1 -1 -2 -3

21. Some of the greatest atrocities in history have been committed in the name of religion and morality.

+3 +2 +1 -1 -2 -3

## *Appendix VI*

### **The Interview Verbatim**

#### **Interview M<sub>5</sub>**

**I:** Bonjour. J' aimerais commencer ma première question en vous demandant quels sont les plaisirs, les joies dans le processus d'être parent en général?

**Mother:** En général? De penser aux enfants, de les aimer ...des les gâter. Je voulais toujours avoir des enfants .....on m'a apporté beaucoup des choses dans ma vie, j' ai changé ma perception. Quand on n'a pas des enfants on est égoïste.

**I:** Est-ce qu'il y a quelque chose de particulier dans ces plaisirs d'être parent qui vous touche le plus?

**Mother:** Le plus heureuse c'est quand je suis avec les enfants en famille, j'adore ça, on partage, on parle, on discute, on joue, ça c'est le plus grand plaisir on parle beaucoup dans la famille, on joue beaucoup. Ils m'apportent beaucoup dans ma vie, j'ai jamais pensé avoir quatre enfants.

**I:** Maintenant, on va un petit peu parler de quelles sont les difficultés dans ce processus d'être parent, les situations qui pour vous sont difficiles à gérer, problématiques autrement dit.

**Mother:** Les chicanes ....les difficultés à gérer les émotions ça c'est difficile pour les parents .... parce que chacun a sa mentalité, on vit ensemble c'est vrai.....la difficulté est à les faire comprendre que la vie ce n'est pas comme ça, ça peut arriver plus tard, il faut attendre, les enfants sont comme tout de suite, chercher à gérer tous les quatre ça prend beaucoup de sagesse et de patience

**I:** Est-ce qu'il y a quelque chose que vous rende le processus de parentage difficile?

**Mother:** Pas vraiment parce que je me suis préparée pour ça, c'est sur que la vie est dure, mais j'aie décidé d'avoir beaucoup d' enfants, il ne faut pas paniquer, il faut prendre ça d'un bon côté parce que moi je prend ça du bon côté ça m'aide à être plus dans l'ambiance

**I:** Maintenant que vous avez un enfant malade du cancer, comment vous décrivez le processus du parentage?

**Mother:** C'est le plus gros failli que j'ai eu dans ma vie...je n'attendais pas ça, malgré que de son enfance je savais qu'il était malade mais quand même j'ai écouté ça dans la radio et à la télé qu'il y avait des enfants malades de leucémie mais je ne m'attendais pas à ça, que ça arriverai à moi. On se sent impuissante, on se sent frustrée, on se sent arrogée, on ne pense pas que ça peut nous arriver on dit pourquoi....pourquoi nous, puis pourquoi lui ....on ne peut pas aider la personne, c'est dur.....beaucoup de stress...tu ne sais pas quoi va arriver....malgré qu'il va bien ça me dérange l'inconnu. L'impact est qu'on se sente impuissante, on n'est plus capable de gérer ça, on se demande pourquoi, on essaie de trouver le pourquoi...

**I:** Vous comme maman comment vous percevez votre rôle dans cette situation spécifique?

**Mother:** C'est dur...je ne peux pas dire moi dans mon cas que je pense à ça mais c'est sûr qu'il y a des parents qui y pensent,....on va gagner.....Je me sens comme maman poule maintenant, on est toujours là, les oreilles, les yeux, on est à l'alerte, on apprécie plus les enfants, on est plus attentif, on est plus compréhensif, on essaie de comprendre chaque enfant....être mère ça veut dire faire face avec ça, de gérer ça et de mettre l'ambiance vraiment agréable

**I:** Est ce qu'il y a quelque chose en particulier que vous cause des problèmes?

**Mother:** Le traitement de chimiothérapie.....ça tue son système immunitaire on n'a pas le choix....il est complètement à l'écart de tout le monde.....

**I:** Est-ce qu'il y a d'ambiguïté ou de confusion par rapport à votre enfant malade?

**Mother:** Oui, il ne parle pas, il ne s'exprime pas.....c'est moi qu'il doit comprendre, qu'il faut dépister. Il a mal à la tête, il va pleurer mais il ne peut pas me dire « j'ai mal à la tête ». L'incertitude il y a beaucoup.....comment ça passe à lui....j'ai tous les informations mais on n'est pas capable de gérer ça, comment qu'on peut lui aider passer à travers ...c'est de lui aider à pas souffrir.....qu'est-ce qu'on fait....ça peut arriver d'un moment à l'autre.....on sait pas.....

**I:** Quand vous sentez l'incertitude, l'ambiguïté et la confusion que ça viennent, comment vous faites face à ça?

**Mother:** Je pleure .....je pleure..... je parle aux personnes je demande de l'aide

**I:** Eh si maintenant je vous demande de me parler comment vous imaginez votre vie dans le futur toujours par rapport au processus de parentage, est-ce que ça va être plus difficile, plus facile? Comment vous imaginez ça dans les années qui vont suivre?

**Mother:** J'espère que ça va mieux.....je veux rester positive.....je vois l'avenir en peu grand.....avoir les enfants grandir....de participer aux activités ....c'est l'inconnu que me fait peur.....après sa maladie comment ça va être.....on ne sait pas.....est-ce qu'il va être capable, normal une fois grandi.....est-ce qu'il va être bien.....

**I:** Quels sont les conseils ou les suggestions que vous pourriez donner aux personnes qui ont les mêmes problèmes comme vous afin de les aider, les soutenir?

**Mother:** De prendre ça du bon côté, de parler, de pleurer, de crier, de demander de l'aide. Il y a des organismes et des personnes, de ne pas garder ça dedans pour ça, il faut demander de l'aide, quand il faut pleurer, pleurer, essayer de parler et de pleurer.....

**I:** Est-ce qu'il y a d'autre chose que vous voulez ajouter ?

**Mother:** C'est dur pour la vie du couple.....on peut pleurer.....mais pour les hommes ce n'est pas pareil on garde ça dedans....c'est ça qui est dur dans la vie du couple quand on a un enfant malade.....c'est ça.....ce n'est pas facile de gérer tout ça.....

**I:** Est-ce que vous avez terminé?

**Mother:** Oui, oui

**I:** Merci beaucoup

*Appendix VII*

**QUESTIONNAIRE ONE**

**A PROJECTIVE TEST**

*Participant's Number: F<sub>1</sub>*

## SENTENCE INTERPRETATIONS

### Instructions

You are going to see a series of sentences, and your task is to tell a story that is suggested to you by each sentence. Try to imagine what is going on. Then tell what the situation is, what led up to the situation, what the people are thinking and feeling, and what they will do. In other words, write as complete a story as you can, a story with plot and characters.

You will have twenty (20) seconds to look at a sentence and then four (4) minutes to write your story about it. Write your first impressions and work rapidly. I will keep time and tell you when it is time to finish your story and to get ready for the next sentence. There are no right or wrong stories or kinds of stories, so you may feel free to write whatever story is suggested to you when you look at a sentence. Spelling, punctuation, and grammar are not important. What is important is to write out as fully and as quickly as possible the story that comes into your mind as you imagine what is going on. Notice that there is one page for writing each story. If you need more space for writing any story, use the reverse side of the paper.

\* Note: the following questionnaire is an example of a father (F<sub>1</sub>) who was qualified as an uncertain-oriented person

- 1. TWO PEOPLE ARE WORKING IN A LABORATORY ON A PIECE OF EQUIPMENT.

*Sentence Number: 1*

*Participant's Number: F<sub>1</sub>*

1. What is happening? Who is (are) the person(s)?

There is a problem with a piece of the equipment and they try to find a way to solve the problem  
(2 employees are involve)

2. What has led up to this situation? That is, what has happened in the past?

The machine is always broke and they try to repair the machine

3. What is being thought? What is wanted? By whom?

They not want problem anymore because the boss will fire them

4. What will happen? What will be done?

They will repair the machine and everybody will happy



2. **A PERSON IS SITTING, WONDERING ABOUT WHAT MAY HAPPEN.**

*Sentence Number:2*

*Participant's Number: F<sub>1</sub>*

1. What is happening? Who is (are) the person(s)?

The person (secretary) is afraid of losing her job because she is not good and she did some mistake

2. What has led up to this situation? That is, what has happened in the past?

She always late in the morning and she have to arrive on time

3. What is being thought? What is wanted? By whom?

The boss told her not to arrived late because she will be fired. She should be on time

4. What will happen? What will be done?

She will make effort to arrive on time and she will keep is job

3. **A YOUNG PERSON IS STANDING: SOME KIND OF OPERATION CAN BE SEEN IN THE BACKGROUND.**

*Sentence Number 3*

*Participant's Number F<sub>1</sub>*

1. What is happening? Who is (are) the person(s)?

A parent are looking through a glass the surgery of their son going on

2. What has led up to this situation? That is, what has happened in the past?

The parent ask the doctor to watch the surgery and the doctor accept

3. What is being thought? What is wanted? By whom?

The parent want to make sure that everything is going well and they doing everything they can

4. What will happen? What will be done?

The surgery will go well and the parent enjoyed be there during surgery

4. A PERSON IS THINKING: AN IMAGE OF A CROSSROADS IS IN THE PERSON'S MIND.

*Sentence Number: 4*

*Participant's Number: F<sub>1</sub>*

1. What is happening? Who is (are) the person(s)?

The person is alone in the middle of an intersection thinking where he can go

2. What has led up to this situation? That is, what has happened in the past?

The person can take the direction he want in is life any direction is good but all different

3. What is being thought? What is wanted? By whom?

He don't know what he want but he know that one direction will changed is life so

4. What will happen? What will be done?

He didn't take any direction because is was afraid is stay in the middle and he blame a boring life

## Appendix VIII

Theme/Category	Verbs
Pleasures » providing education/values	<ul style="list-style-type: none"> <li>• is just to give them a good education (F1)</li> <li>• finalement de leur donner tout ça qu'on peut pour la propre vie avec un bagage, un meilleur bagage qu'on peut leur donner (M2)</li> <li>• to educate as much as possible (F3)</li> <li>• l' éducation (M7)</li> <li>• qu'ils sont bien éduqués (F9)</li> <li>• de leur donner une bonne éducation (M9)</li> <li>• des les éduqués de la même façon et de leur montrer des belles choses, de mieux qu'on a appris (F15)</li> </ul>
Pleasures » sharing love	<ul style="list-style-type: none"> <li>• one to each other that gives a kiss to each other (M1)</li> <li>• nice words just "I love you" (M1)</li> <li>• the love also that they give you (M1)</li> <li>• I would say basically the hugs and kisses (M3)</li> <li>• I wish to give them everything, so that's why I feel great now, give them love (F4)</li> <li>• they give me so much pleasure every time, for example they write to me a little note (M4)</li> <li>• they call me at work (M4)</li> <li>• they make a little drawing (M4)</li> <li>• je suis content d'être parent, mes enfants me rendent heureux (F5)</li> <li>• de penser aux enfants, de les aimer ...des les gâter (M5)</li> <li>• la reconnaissance de l'enfant par rapport au parent cela apporte beaucoup de l'amour, de joie, ça fait chaud au cœur d'attendre un enfant de dire merci pour le respect que tu m'a montré (M7)</li> <li>• Le matin quand je vais les réveiller et ils me donnent des bécus puis qu'ils me disent bonjour maman, puis que je leur donne un million de bécus avant s'aller à coucher....n'importe quoi, pour moi être mère c'est une grande joie toute la journée (M8)</li> <li>• I always enjoy, I love them, I adore them (M10)</li> <li>• when the child seeks affection and when she says "mummy I love you" (M12)</li> <li>• Quand nos enfants nous donnent des caresses que nous apportent beaucoup d'affection (M14)</li> <li>• It's always a good moment at Christmas, at their birthdays, at the evenings when he tell us and he says "I love you" (M16)</li> <li>• les enfants sont le bonheur de la famille, ça nous rendre heureux (F17)</li> <li>• I am very happy to give them the opportunity to enjoy life as I did my self so, I do share with them, I like to please them, I like to see them happy (F1)</li> </ul>

*Sample Flexible Analysis System, Cross-Reference between Themes/Categories and verbs discussed by subjects during the interviews sessions.*

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