

# “The worst experience”: The experience of grandparents who have a grandchild with cancer

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## Abstract

*This study explored the experience of eight grandparents having a grandchild diagnosed with cancer. Semi-structured interviews, both with individuals and couples, were used to gain a better understanding of the meaning these grandparents give to this experience. A thematic analysis based on Giorgi's (1997) phenomenological method highlighted three central themes: “Living the worst experience”, “Having to support: A crucial role for grandparents”, “To feel supported to better carry on.” The results of this study can contribute to enhancing the quality of care for grandparents affected by their grandchild's cancer.*

According to a study by The Vanier Institute of the Family (2000), Canadian grandparents enjoy regular contact with their grandchildren and this remains an important source of health and well-being. They also represent a segment of the population that is increasingly younger, healthier and more numerous. American studies reveal that the majority of grandparents perceive their grandparenting role as essential to their lives and that their grandchildren help them deal better with the aging process. The birth of a grandchild provides grandparents with various meanings such as the survival of the family lineage, a sense of immortality and continuity of life, and a reason for living (Kivnick, 1982; Kornhaber & Woodward, 1981). In a more recent study, Baydar and Brooks-Gunn (1998) demonstrated that the involvement of grandmothers with their grandchildren remained important in spite of their multiple social activities.

Certain social and structural factors are the basis for the various meanings and behaviours associated with the experience of being a grandparent. Some of these factors are geographic proximity (Uhlenberg & Hammill, 1998), quality of the relationship between the grandparents and the parents, grandparent sex (Kornhaber & Woodward, 1981; Uhlenberg & Hammill, 1998), family lineage (Fisher, 1983; Uhlenberg & Hammill, 1998), race and ethnic group, grandparent marital status, number of grandchildren in the family (Uhlenberg & Hammill, 1998), grandparents' health status (Creasey & Kaliher, 1994; King & Elder, 1998; Sanders & Trygstad, 1993) as well as the age of the grandparents (Sanders & Trygstad, 1993) and that of the grandchildren (Creasey & Kaliher, 1994). Interestingly, none of these studies highlighted the grandchild's health status as a factor having a potential influence over the grandparenting experience. It's no wonder very little research could be found about the actual experience of grandparents in the context of childhood cancer.

Articles on children with cancer may present some information on the grandparents but, for the most part, these are anecdotal and more likely to be based on clinical observations by health professionals than on the grandparents' subjective experience. Only two empirical studies (Faulkner, Peace & O'Keeffe, 1995; Martinson, 1998) were found to relate the experience of grandparents with a grandchild with cancer. Faulkner et al.'s (1995) qualitative study sought to better understand how family members, including 15 grandparents, manage a child's cancer diagnosis. This British study reveals that grandparents' unique experience is characterized by the pain they

experience when seeing their grandchild and their own child suffer. Martinson (1998) interviewed 19 Taiwanese grandparents to explore their own comprehension of the illness of a grandchild with cancer and the type of support they could provide to the family. This descriptive study demonstrated that most grandparents provided support to the families by taking care of the siblings, caring for the sick child or providing financial support. However, these two studies have limitations. They were conducted in foreign countries and do not specify the grandchildren's ages nor their cancer prognosis.

Other studies have been completed with grandparents in situations where their grandchildren were born prematurely or suffered from a disability. These studies indicated that the grandparents were greatly perturbed by these health situations. The whole sense of family continuity is shaken up by such an event (Katz & Kessel, 2002; Prudhoe & Peters, 1995; Rempusheski, 1990; Schilmoeller & Baranowski, 1998; Vadasy, Fewell & Meyer, 1986). If these few studies demonstrate that the premature birth or disability of a grandchild are troubling situations for the grandparents, the cancer diagnosis of a grandchild is also upsetting for grandparents, particularly when considering the profound implications accompanying such an event and warrants further studies.

According to Parse's (1981, 1987) writings, from which the researcher derived the philosophical tenets guiding the relevance of this study for the discipline of nursing, increasing our understanding of people's life experiences through research helps develop nursing knowledge and is essential to nursing intervention. The phenomenological approach is particularly appropriate when a study aims to explore the subjective meaning of a phenomenon from the perspective of the participants to develop nursing knowledge (Parse, Coyne & Smith, 1985). Thus, the purpose of this phenomenological study was to describe and better understand the meaning given by Quebec grandparents to the experience of having a grandchild with cancer. The lack of knowledge about the grandparents' experience in the area of childhood cancer within the North American context was the main incentive behind the completion of the study.

## Method

The qualitative research methodology chosen for this study is phenomenology. Instituted by Husserl (1976) at the beginning of the 20th century, phenomenology is a philosophical approach that

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considers the subjective lived experience of phenomena as the source of knowledge. Phenomenology seeks to describe and better understand the meaning participants give to their lived experience, without altering its nature, from the awareness the person has of it and as related in their stories, biography, and life environment. Husserl (1970) states that we are in the lifeworld (*Lebenswelt*), that is to say the lived world, the backdrop to all our perceptions, experiences, and knowledge. Giorgi's (1997) data analysis method, which is described further below, corresponds with Husserl's philosophical tenets and allows from the narratives to enter in the subjective world of the individual who relates his or her actual experience, the meaning the individual ascribes to it, and how he or she did so.

Eight grandparents agreed to participate in the study. They were recruited with the help of a non-profit organization that promotes the wellness of children with cancer and their families. The inclusion criteria used to select the participants were as follows: 1) to be a grandparent of a child aged between four and 12 who is living with cancer at the curative phase of the illness; 2) understands French and able to express oneself with ease in that language; and 3) the child was diagnosed with cancer within the last two months. A coordinator for the organization invited grandparents who came to the oncology clinic of a pediatric centre to participate in the study. Letters were also sent to the parents who were members of the organization asking them to discuss the existence of the study with their own parents (i.e. grandparents). Eligible grandparents were then invited to contact the researcher by phone. During this telephone contact, the researcher would provide information on the study goal and procedure. Ethics approval from the University ethics committee was obtained.

The data collection took place in the grandparents' natural living environment. The semi-structured interviews were organized around general questions such as: "Please describe the circumstances surrounding the disclosure of your grandchild's diagnosis." Altogether, five interviews were conducted by the researcher: three with couples (n=6 grandparents) and two with individuals (n=2 grandmothers). The eight grandparents were between 56 and 69 years old and were all retired. Two grandmothers had remarried following the death of their first spouse, therefore the male spouses interviewed were not the ill children's biological grandfathers.

The data from the interviews were subjected to a thematic analysis in keeping with Giorgi's data analysis method (1997). This method includes several steps: 1) transcribing the interviews comprehensively; 2) immersing oneself in the general meaning of the participants' narratives; 3) selecting semantic units by isolating frequently used words, phrases or ideas to organize and describe these units; 4) transforming the participants' spontaneous expressions into

more abstract expressions that reveal their meaning; and 5) synthesizing the semantic units (themes) into a consistent and invariable description (essence) of the phenomenon under study.

According to Giorgi (1997), the scientific rigor of a phenomenological study is supported by using authenticity and credibility criteria. Authenticity is defined as the consistency between the findings and the lived experience as described by the participants in the study. The criterion of authenticity was observed by reading the interviews multiple times and by comparing the researcher's analysis results with those of the research supervisor. The criterion of authenticity can also be obtained through "bracketing". Bracketing is an exercise where the researcher attempts to suspend his/her own preconceptions to break away from the certainties that fill one's consciousness about the phenomenon under study. It was also used to meet the criterion of authenticity (Deschamps, 1993). Credibility means that the results match reality and is obtained, among other things, by having certain diversity in the selection of participants and having the phenomenon recognized by experts. Another method of ascertaining the credibility of findings is using interviews until data redundancy is achieved (Giorgi, 1997). The researcher acknowledges that the limited number of participants did not produce the diversity and redundancy expected from phenomenological qualitative studies. Eight grandparents were, nevertheless, sufficient to capture the essence of the phenomenon and the themes identified from the data analysis cover common interpretations of the actual experiences expressed by the grandparents. Incidentally, we must remember in phenomenology that the goal is to give a faithful description of the actual experience so as to better understand the phenomenon; one is not to predict, control, give causal explanations, generalize or define (Ribau et al., 2005). To obtain recognition of the phenomenon by experts, the results were compared to those of authors known for their scientific papers identified in this particular domain and discussed with the research supervisor who is a psychosocial oncology nurse researcher. However, there is one limitation to this study that needs to be mentioned: the recruiting process did indeed promote the participation of grandparents already involved and devoted to the diagnosed grandchild and his or her family, which may well constitute a bias in this study.

## Results

The essence of the phenomenon is described as follows: having a grandchild with cancer is, for all the grandparents in the study, the worst experience they can ever live, a vital duty to support members of the family, a duty that is closely related to the perception they have of their grandparental role, and a need to feel supported by calling upon several strategies to better carry on. Three central themes and related subthemes are presented in Table One.

### 1. Living the worst experience

All participants in the study declared that having a grandchild with cancer is an extremely difficult experience, or perhaps even the worst experience that grandparents can ever go through. Out of the eight participants, five said explicitly that having a grandchild with cancer "is the worst thing of all." Learning that their grandchild had cancer is described as "a tragedy", as "if the earth had opened up", "the earth had crumbled down", "the world had stopped turning" or, as one stated, "being in a head-on collision". This theme is very well-illustrated by one participant's account who, in spite of having lost her first husband and her son hardly four years before, stressed that the experience of having a grandchild with cancer, is "the worst hardship she's ever lived."

*"Now that was the worse of the worst of them all. It is worse than having lost my own son, it is worse still than having lost my husband. Of all I have gone through to date, Maxime's† (her grandson) hardship, it is the worse one. It is the worst one and I can't bring myself to accept it."* (Mrs. Rochon)

**Table One: What it means for grandparents to have a grandchild with cancer**

Central themes	Subthemes
1. Living the worst experience	<ul style="list-style-type: none"> <li>• Living a whole array of emotions</li> <li>• Feeling an overwhelming sense of injustice</li> <li>• Feeling powerless</li> <li>• Living under the sword of Damocles</li> </ul>
2. Giving support: A crucial role for grandparents	<ul style="list-style-type: none"> <li>• Getting involved by offering instrumental and emotional support</li> <li>• Hiding behind a screen</li> </ul>
3. To feel supported to better carry on	<ul style="list-style-type: none"> <li>• Talking about it</li> <li>• Believing in something</li> <li>• Getting information</li> <li>• Rationalizing</li> <li>• Living in the present</li> <li>• Taking one's mind off things</li> </ul>

### *Feeling a spectrum of emotions*

Since diagnosis, the grandparents have been overwhelmed by a deep sadness that revealed itself in the tears some of them shed during the interviews. Some expressed their pain with expressions such as “it breaks my heart”, “it hurts me a great deal to see him like that” or “the tears flow and the flood gates open up.” Their grandchildren’s illness has also thrown them into a dreadful fright where “fear is constant” and where one is “afraid of everything.” There remained a persistent and unchanging concern for the child’s future, for the debilitating effects of cancer and its treatments, and the child’s quality of life, both in the short and long term. Six participants out of eight stated that they consider cancer to be an incurable disease. Cancer “is always frightening” because “you see death.” Four grandparents added that some of their loved ones had died of it. Finally, all the participants claimed they were feeling a lot of anger. Four grandmothers out of five reported the “aggressiveness”, “anger”, “revolt”, and “rage” they felt upon hearing the diagnosis and how hard it is for them to “accept their grandchild’s disease.”

The suffering described by the participants takes on different forms: suffering for themselves, for their child, for the diagnosed grandchild, for the couple and their other grandchildren. The grandparents declared suffering much themselves, this pain being so strong that “there are no words fit to express it.” They claimed to be deeply affected by the situation. Their grandson “is that important” in their lives. The grandparents’ experience appears to be as difficult to endure as that of their daughter or son, the child’s parent.

“... he (the child’s father) took his two children in his arms and started to cry and cry. ...So, for me, the grandmother, it’s so tough. Because I know everything he is feeling but that he won’t express. He does not really want to talk about it. Because it boils down to the fact he is afraid.” (Mrs. Limoge)

Nevertheless, the eight participants declared that the most difficult aspect of the whole experience was to see their grandchild sick. To witness the child’s suffering, the effects the disease has on his/her life, to see the child “suffer all this trauma” and “all the suffering associated with the chemo”, it is “Hell”, “inhumane” and “too painful” for them. The following verbatims clearly demonstrate the suffering felt for the diagnosed grandchild.

“Me, I remember when we used to go see him (the grandson), with tubes all over... To me, this little kid has had to endure so much pain. This kid has suffered. Two-and-a-half months in the hospital. It was terrible, all the complications he had. ...He is already aware that he is not as tall as the others. It hurts me so.” (Mrs. Limoge)

“Well, it is for the child that I find it so dreadful. It represents two years of her life all the same. Especially the last year, it was very hard because she was so tired. ...poor Julie (the granddaughter), I felt quite sorry for my dear little sweetie. Because I found that so hard...” (Mrs. Nadeau)

The grandmothers seemed to be particularly afflicted by their grandchildren’s illness. One grandmother has lost a lot of weight since the diagnosis was announced, and she was so affected by the sight of her grandson vomiting that she would end up vomiting too. Another mentioned that at times it was impossible for her to go to the hospital because she would “come out of it too destroyed”. Yet another said she suffered more from it than her granddaughter herself.

For some participants, the couple was also suffering. One grandfather said that his spouse’s very aggressive attitude “was making sparks” within the couple and contended that it was very hard to live. One participant confided that her relationship with her husband had deteriorated since the diagnosis. She added that since her grandson had taken ill, she felt like she “was suffocating” and she wanted to be all alone. Without being able to explain it, she felt her

spouse “was stressing her out” and said she had become estranged from him, while he believed that she ought to stop “worrying and talking about it” so that it would be less painful for her.

The grandparents also said they were deeply touched by the reaction of their other grandchildren – the siblings of the diagnosed child – who were greatly affected by their parents’ absence and overwhelmed by an inexpressible pain.

“...I still remember the evening when she (the diagnosed child’s little sister) hid behind the door with her brother’s picture and just cried. There was not a single evening when she did not go to bed without that picture either next to her, in her bed, or on a small chair, there. It touches you deep inside, really.” (Mr. and Mrs. Lebon)\*

### *Feeling an overwhelming sense of injustice*

The grandparents reported how very difficult it was for them to accept that their grandchild had cancer. For six of the grandparents, this situation seemed absolutely unjust, unthinkable, insane, even “not normal”.

“It’s totally unjust. There are elderly people who are begging to die, there are homeless people who are starving, and there are people whose suffering knows no end. He does not come to get them, he comes to get a poor little grandchild. It’s so unfair. I know we all live on borrowed time, but for longer than this. Don’t just stick him under our noses and then come to reclaim him.” (Mrs. Rochon)

“...I say to myself this is not normal. ...that this should happen to her, I am totally outraged. I find that there is no justice on earth. Utterly unjust.” (Mrs. Nadeau)

### *Feeling powerless*

The eight participants talked about the feeling of powerlessness they felt about their grandchild’s illness. They found it hard not to be able to “do anything” when they “would give up their own lives for their grandchildren.” Six grandparents said they wanted to remain strong and fight for the child, while two grandmothers expressed the idea that they wished without the shadow of a doubt that they could “take on their grandchild’s illness”.

“He (her grandson) was in a dreadful state, eh. It was very, very hard. So you are there, you carry a weight and you can’t do anything, that’s powerlessness. There, you can’t see him, when they are in intensive care. That’s when you feel powerless, you feel like you’re behind the door, you feel like dirty laundry.” (Mrs. Limoge)

“Health is what we would love to give him, that’s so much more. But if we could. You feel totally powerless. I told Julien (her grandson), if grandma could, she would take on your illness right away.” (Mrs. Gervais)

### *Living under the sword of Damocles*

Four grandparents explicitly expressed they were reduced to “Living with the sword of Damocles” over their heads. All grandparents in the study mentioned the importance of hope in the painful experience of having a grandchild with cancer. Despite the fact that their grandchild was better or responded well to the treatments, they were constantly dreading the possibility that the child would not heal or that he or she would have a recurrence.

“...the success rate at his age, they say is pretty good. So that’s what I find the most encouraging. But I always have a doubt in my mind; it’s at the back of my mind, as if the sword of Damocles is over my head.” (Mr. Rochon)

“So, for almost three years now, we live in constant fear. Me, I don’t live it well at all. The fear of a recurrence. Julien (her grandson) he actually had one. And we continually question, in spite of medical competence, in spite of the means we have at our disposal nowadays.” (Mr. and Mrs. Limoge)\*

*“You try to put this behind you. And to be optimistic for the future. To always keep hope. Well, it’s not easy, but to remain hopeful. We take advantage of every moment with him. Hoping that everything will go well. At the moment, things are going well. But later, when he’s older, I am certain it will bring other complications.”* (Mr. and Mrs. Lebon)\*

## 2. Having to support: A crucial role for grandparents

This second theme unveils the fundamental need for every participant to support all members of the family. They even go as far as making it a duty, because they perceive it as one of the most important aspects of their grandparental role. The importance of support corresponds to established family values prior to the diagnosis and has been reinforced since. They perceived their grandparental role as very important and saw themselves as the “pillar” of the family. They feel useful, indispensable and available, particularly because they are retired. In this light, they believed that family members “could not pull through” without their help. In fact, all grandparents were the first loved ones to whom the parents announced the sad news. The eight participants stated “placing themselves at the service” of their grandchild and his or her family. Indeed, all the grandparents in the study were very involved with their grandchildren. As grandparents, they are still involved, but from then on they had to “get even more involved,” because their child and grandchildren needed them more than ever before. Some even said they had always had a “special relationship” with the diagnosed grandchild. Some declared “forgetting themselves” or “scheduling their lives” for the diagnosed grandchild.

*“Now I get even more involved because my daughter, she couldn’t do it all alone as she has another one at home. There is the other one who goes to school; he also needs his mother, you know, he needs us. What about the people who don’t have parents or whose parents live far away. I don’t know how they manage. Grandparents must get involved. It’s important, seems to me like the children can’t pull through if the grandparents don’t get involved.”* (Mrs. Gervais)

*“Me, I always say we’re there for them. If you need us, at any time, at any hour of the day or night, it does not matter, we’re going to be there. We’ve been saying that since he was very young.”* (Mr. Rochon)

### Getting involved by providing instrumental and emotional support

All eight participants reported providing instrumental and emotional support to all the members of the family. Their instrumental support is provided by caring for the siblings, taking the place of the parents when the child was being hospitalized or accompanying the child for medical visits. Six grandparents mentioned that they were there every day of their grandchild’s hospital stay. They gave emotional support through listening, encouragement or “comforting words.”

*“We took care of the little one (the diagnosed child’s sister). We tried to encourage her. Then we took her often to the hospital. I would make small lunches and we would go and eat with her mom, so that she would see her mother too, eh. Because N. (the mother) slept at the hospital almost all of the time. And my husband slept in the hospital room with the little one so that she (the mother) had a chance to get some rest.”* (Mr. and Mrs. Lebon)\*

*“He (the father) comes here twice a week, he comes with the little ones... you know, for the last two years, I have been the one doing the laundry and he (the grandfather) takes care of the kids. ...if we are close to them, we don’t necessarily have the solution, but it helps at least a bit with the morale. Each time I would leave the hospital, he (the grandson) would say to me: until next time, you’re going to come back, I love you. And I would answer: I love you too. So these are just words, but they are comforting nonetheless.”* (Mr. and Mrs. Limoge)\*

### Hiding behind a screen

The eight grandparents in the study said in their own words they wished to protect family members by providing them with a more livable environment. To that end, they choose to silence their own suffering or worries by avoiding crying in front of their children and grandchildren or talking about certain topics in order not to hurt them or exacerbate their stress. To express this attitude, one of the participants used the metaphor “hiding behind a screen”, which was retained as the label for this subtheme. For one female participant, protecting the family requires a great deal of courage on the part of the grandparents, and sometimes it deprives them of information on the child’s status.

*“I hide behind a screen. So, this way, it does not show. Instead of falling apart in front of him (their grandson), it is best to leave. No, it’s going to trouble him.”* (Mr. and Mrs. Rochon)\*

*“One must find courage for our children, for our grandchildren. They need not see all the hurt we’re feeling. I would not want Julien (her grandson) to know my heart is breaking, that I don’t sleep because he is ill. We always have a big smile on and then we have to encourage them all the time. Me, as a grandparent, I find that you can’t ask all the questions you’d like to ask because you don’t want to be adding our own anxieties to their burden.”* (Mrs. Limoge)

## 3. To feel supported to better carry on

All the grandparents stressed that it was crucial to feel supported to successfully get through the terrible experience of a grandchild’s cancer. The support, presence, and listening of their spouse, family members or friends helped them “carry on.” The three couples interviewed said they helped each other and showed obvious signs of complicity during the interviews. However, some grandparents reported that they must sometimes ignore their own support needs to adequately support the grandchildren and their parents. Two participants mentioned that few psychological resources or services were available in case of need.

*“Us grandparents, it’s true we are left to the side, but we suffer a great deal for our grandchildren and children. So if we could have a small organization or something of the kind where we could talk about it, too. We must always keep everything inside us. I know there are professionals who offer their help, but it’s only for the children and parents, but not for the grandparents because people think we are excluded from that, but on the contrary. We form a whole, so when it comes to professional assistance, I think it should also exist for grandparents.”* (Mr. and Mrs. Limoge)

The grandparents reported using several strategies to help them cope with the situation. Four of them mentioned they find it necessary to talk about it and confide in loved ones to help them through such an ordeal. They did not always want to do so with the children’s parents for fear of becoming one more burden for them.

*“They (the grandparents) should talk about it among themselves. If they are a couple, the man and the woman, the grandfather, the grandmother should talk about it between themselves and with the other set of grandparents too. On both sides if they can. Because we need to address this. Even if we can’t do it with our own children, we need to talk about it.”* (Mrs. Limoge)

The grandparents indicated the importance of believing in something to help them overcome their pain and worries. Six participants out of eight said they believed in the ability of medicine to cure their grandchild. Three grandparents reported that their religious beliefs had given them good comfort.

*“I must hang on to something. I have never really been a regular churchgoer, but I saw there was a chapel. I went in twice. My husband said you’d better hang on to the physicians instead. Of course, they*

*are the ones who take care of them with the nurses. We have to put most of our faith in them. But I say: it can't hurt to think there is someone up there who takes care of our grandchild too. In my father and my mother..."* (Mrs. Gervais)

Getting informed about the situation was also important to help them cope better with the situation. Three grandparents indicated that they used the internet to learn more about the etiology of the disease and treatment success rate. The interviews helped reveal that they knew a great deal about the grandchild's status and illness, and that they were comfortable with using medical jargon.

*"I went on the internet, well, everything I could find on the bloody disease. Especially what dealt with the drugs. Then I would look on the internet what these drugs she was taking were used for. I had made a little list and I would look things up."* (Mrs. Nadeau)

The three grandfathers in the study reported on the way they would rationalize the situation to help them ease the tension; they were seeking "solutions", "tools", and a "logical element". Four grandparents stated they were living in the present as they lived "day to day" "step by step" in order to fully enjoy their grandchild's presence.

## Discussion

The data analysis showed that the eight participants are facing one of the worst experiences in their lives. The results of the study underscore the suffering participants experienced since their grandchild was diagnosed with cancer, a painful experience that reinforces the significant value of family and the support that should be provided to all family members. It is an experience that requires people to use several strategies and resources to better cope with the situation. The grandparents are deeply affected by their grandchild's malignant disease and, in that respect, it would seem that living through this experience is as difficult for them as it is for the children's parents. The findings of this study demonstrate that the grandparents' pain is comprehensive in that they feel pain for themselves, their children's relationship and their other grandchildren.

The participants interviewed in this study reported a strong reaction to the communication of the cancer diagnosis and a fear borne out of the notion that cancer is an incurable disease. The child has hardly begun his or her life and is already struck by a potentially life-threatening disease. As the cancer event is not taking place within the logical conception of life and death, the grandparents are deeply affected by a sense of injustice. Such a threat disrupts the sense of family continuity and "immortality through clan" in the grandparents. Faulkner et al. (1995) and Vadasy (1986) had a similar finding in their studies. Despite their wishes for the grandchild to get through unscathed, the grandparents' hope is rather precarious. They are constantly anticipating the worse. The Damocles syndrome was mostly mentioned in the documentation about parents of children with cancer (Koocher & O'Malley, 1981).

Supporting other family members is a duty described by grandparents in the study. The significance attached to family relationships and interpersonal involvement suggests that family values have been incorporated into their lives and play a vital role. The cancer diagnosis of their grandchildren revives their conception

of the grandparental role as familial and personal resource. Their grandchildren are at the heart of their lives, a reason for living also identified by Kivnick (1982). All the grandparents participating in the study also talked about the intense relationship they shared with their own child and their sick grandchild. They must cope with a very worrisome situation that brings suffering to their loved ones. The grandparents choose to devote themselves entirely to their grandchild and make it their duty to support him or her. However, one should be careful in interpreting these findings as the recruiting process may have introduced a bias: grandparents referred to the researcher may have been those that were already very involved or had time to devote to their families. Some studies reviewed also report on the support that grandparents provide to their families when a grandchild is diagnosed with cancer, however none address the perceived sense of duty that is associated with the grandparental role.

The grandparents in the study reported providing support to all the members of the family, a support that is both instrumental and emotional. They declared that they sometimes would silence their own suffering in order not to exacerbate that of their loved ones or not to hurt them further. Reports in the area of childhood cancer or disability corroborate the grandparents' desire to protect family members, stating that the grandparents may be unwilling to express their feelings for fear of shocking or hurting their children and grandchildren (Harris & Curnick, 2000; Katz & Kessel, 2002; Rempusheski, 1990).

The findings also highlight the crucial need for the grandparents to feel supported in order to better cope with the situation. The members of the couples in our study helped each other a great deal, but tensions and conflicts could occur due to the intensity of the grandchild's medical situation. Half of the interviewed grandparents found it difficult at times to satisfy their own need for support as they had to support others while needing support themselves. The researcher observed that many of the grandparents in the study said that participating in the research did them some good. It may be that the confidence established between the researcher and the participant provided a support not available in the current health system. Workshops or self-help groups for grandparents could be useful to help them express their confusion and feel they are not facing this painful situation alone as suggested in studies by Schilmoeller and Baranowski (1998) and Vadasy et al. (1986).

## Conclusion

The experience of grandparents who have a grandchild with cancer has received very little empirical exploration in the past. As these grandparents' actual experience covers a wide spectrum, nursing would benefit from in-depth qualitative studies in this area that should include a much greater number of grandparents. The findings are an invitation for nurses to support, through their presence and compassion, grandparents living with a grandchild with cancer. While the duty to be by the side of their grandchild is revived as a dominant value for these grandparents, it is also a source of worry and suffering. ♣

† All the names used here are pseudonyms

\* Verbatims with an asterisk contain the remarks shared by the couple

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