



The experience of grandmothers of children with cancer

A experiência das avós de crianças com câncer
La experiencia de las abuelas de niños con cáncer

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How to cite this article:

Mendes-Castillo AMC, Bousso RS. The experience of grandmothers of children with cancer. Rev Bras Enferm [Internet]. 2016;69(3):523-9. DOI: <http://dx.doi.org/10.1590/0034-7167.2016690320i>

Submission: 04-16-2015

Approval: 01-30-2016

ABSTRACT

Objective: to understand, from grandmothers' perspectives, the experience of having a grandchild with cancer. **Method:** qualitative study, guided by philosophical hermeneutics. Eight grandmothers of children who had finished an oncology treatment participated in this study. Data were collected through interviews, which were recorded, transcribed, and analyzed according to the principles of hermeneutics. **Results:** the grandmothers underwent an experience of multiplied, silent, transformative, and permanent suffering. They believe it is their role to be present, but they recognize their adult children's independence and self-determination. Grandmothers highlighted that their experience has been very little accessed and considered by health care professionals. **Conclusion:** we recommend including grandparents in the context of care and in additional research. **Descriptors:** Nursing; Family Relations; Pediatric Nursing; Cancer; Qualitative Research.

RESUMO

Objetivo: compreender, a partir da perspectiva das avós, a experiência de ter um neto com câncer. **Método:** trata-se de estudo qualitativo, guiado pela Hermenêutica Filosófica Interpretativa. Participaram oito avós de crianças que haviam concluído tratamento oncológico. Os dados foram coletados através de entrevistas, que foram gravadas, transcritas e analisadas seguindo os pressupostos da Hermenêutica. **Resultados:** as avós vivenciam experiência de sofrimento multiplicado, emudecido, transformador e permanente. Acreditam que seu papel é estar presente, mas reconhecendo a independência e a autodeterminação do filho adulto. As avós evidenciam que sua experiência tem sido muito pouco acessada e considerada pelos profissionais de saúde. **Conclusão:** recomendamos a inclusão dos avós no contexto do cuidado e a realização de novas investigações. **Descritores:** Enfermagem; Relações Familiares; Enfermagem Pediátrica; Câncer; Pesquisa Qualitativa.

RESUMEN

Objetivo: comprender, a partir de la perspectiva de las abuelas, la experiencia de tener un nieto con cáncer. **Método:** se trata de un estudio cualitativo, guiado por Hermenéutica Filosófica Interpretativa. Participaron ocho abuelas de niños que habían concluido tratamiento oncológico. Los datos fueron recogidos a través de entrevistas, que fueron grabadas, transcritas y analizadas siguiendo las deducciones de la Hermenéutica. **Resultados:** las abuelas experimentan sufrimiento multiplicado, emudecido, transformador y permanente. Creen que su papel es estar presente, aunque reconocen la independencia y la autodeterminación del hijo adulto. Las abuelas demuestran que su experiencia ha sido muy poco accedida y considerada por los profesionales de salud. **Conclusión:** recomendamos la inclusión de los abuelos en el contexto del cuidado y la realización de nuevas investigaciones. **Descriptor:** Enfermería; Relaciones Familiares; Enfermería Pediátrica; Cáncer; Investigación Cualitativa.

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INTRODUCTION

Cancer in children is an event that deeply affects family life in various spheres. Financial difficulties; problems at work; marital crises; changes in routine, roles and family relationships; general uncertainty; and a series of restraints and hardships in daily life are but some examples of sources of stress that affect these families⁽¹⁻²⁾.

Although there are a number of studies that address the effects of cancer in children on families, the focus of these studies has been mainly its general impact on the functioning of the family system and consequences on parents, children, and their siblings⁽²⁻³⁾.

The effect of experiencing cancer in children among grandparents, in contrast, has been very little investigated. In parallel, there has been a growing interest in intergenerational family relationships. A higher life expectancy, enabled by advances in health care, allows for greater contact between grandchildren and grandparents; today, it is possible that up to four generations coexist in a family. Consequently, grandparents have become more active in the family nucleus.⁽⁴⁻⁵⁾

Recent studies have been conducted to understand grandmothers' role and importance in their families in different scenarios and stages in families' life cycle^(4,6), as well as in some specific situations of children's chronic illnesses⁽⁷⁻¹⁰⁾.

Researchers are unanimous in stating that this area calls for additional, deeper, qualitative research, including a higher number of participants and in different contexts of illnesses and cultures.

In Brazil, grandparents' experiences when dealing with their grandchildren's cancer or any another chronic illnesses have not yet been the focus of research. A bibliographical search conducted in three of the main Brazilian databases using the keywords "grandparents," "child," and "illness" did not find any studies, evidencing the scarcity of publications on this subject and lack of more research.

Therefore, a question arises: How is it possible to understand the experiences of grandmothers of children with cancer?

The objective of this study was to understand, from grandmothers' perspectives, the experience of having a grandchild diagnosed with, undergoing treatment for, and living with cancer.

METHOD

This qualitative research was guided by philosophical hermeneutics, which is defined as the art and practice of interpretation⁽¹¹⁾. Philosophical hermeneutics dates from the 17th century and departs from biblical and theological interpretations of text. It is an interpretative and reflexive methodology that hopes that knowledge will emerge from dialogue, in the form of an unexpected discovery instead of a controlled result⁽¹²⁾.

Participants

The participants of this study were grandmothers of children who had been diagnosed with cancer and begun treatment at least one year before the first contact with researchers.

The inclusion criteria were as follows: grandmothers who were close to the families whose child got ill and actively

participated in their families' lives; had followed or participated in the care of the children and their families during that illness; and did not have the custody of the children, that is, grandmothers whose grandchildren were under their own parents' responsibility and safekeeping. We considered as a criterion for exclusion people who were undergoing treatment for potentially fatal illnesses.

The participants were recruited by the snowball sampling technique⁽¹³⁾. In this sampling technique, the first interviewees indicate the next ones; these, in turn, will indicate others, and so on, until the proposed objective is reached ("saturation point"). The saturation point is reached when the new participants begin to repeat contents that have been already mentioned in previous interviews, without the addition of new, relevant information for the study objectives⁽¹³⁻¹⁴⁾.

Participants were invited to participate in the study through phone calls made by the researchers. After explaining the goals of the study and their participation in the research, an interview was scheduled in case the participants showed interest. We gave participants the choice of being interviewed over the phone in case they preferred that.

Procedures for data collection

Data were collected in individual interviews that were made according to the participants' preference. Four of them were made over the phone and four were in-person interviews. The interviews lasted 40 minutes on average. The demographic data and participants' characteristics were obtained; the interviews were recorded and later transcribed.

An open interview was conducted starting from one triggering question: "Please tell me what your experience has been/was like since the day when you found out your grandchild had cancer." New questions were asked during the interview based on interviewees' answers.

Data analysis and interpretation

According to philosophical hermeneutics, data must be interpreted throughout the process of transcribing, reading, and rereading transcripts and field notes, reflecting on the interviews, and creating of interpretations⁽¹¹⁾.

The main focus of hermeneutic research is not to present each participant's individual stories; rather, researchers seek to emphasize the topic or the phenomenon itself. Therefore, in the representation of data, it is not necessary for each participant to be individually identified; instead, their experiences are presented as a whole. Experiences, people, relationships, and contexts are singular and unique; it is important to highlight that contradictions are expected in the context of research in the humanities⁽¹¹⁾.

Ethical aspects

The ethical conduct established by Resolution 466/2012⁽¹⁵⁾, which deals with research involving human beings, was strictly followed.

A Term of Consent was delivered to participants, who were informed orally and in writing about the research. They were also entitled the right to cease to participate in the study at

any time, with no harm done. They were also ensured the possibility of having access to the results of the research afterward, if necessary. The project was submitted to the Ethics Committee of the University of São Paulo's School of Nursing and was granted approval. Data collection only began after the approval was granted.

RESULTS

In this study, grandmothers showed a wide range of feelings and responses to the experience of having a grandchild with cancer. Suffering is apparent among all of them. Regardless of the time between the illness's critical phase and the time of data collection, they were all emotional and cried when remembering details experienced during the discovery of their grandchildren's illness and treatment, as well as their current life, shedding light on the fact that seeing a child with cancer is tough and truly overwhelming for grandmothers as well.

It's my GRANDCHILD... and it's CANCER!

Grandmothers relived and described with clarity the moment when they received the news of their grandchildren's cancer diagnosis. The sentence "my grandchild has cancer" is the expression that makes grandmothers feel "taken aback," devastating and terrifying them a great deal. The illness symbolized the grandchildren's imminent death. The experience of the cancer was seen by them as something terrible, with a very tragic end. Scared and helpless, they witnessed the abrupt arrival of a nightmare in their grandchildren's and children's lives, and in their own lives.

We thought that this illness had come to take our grandchildren because whenever we hear about this illness, just terrible things come along with it... then it was just [the thought] he was going to die, it was the only thought that came to our minds; it was very hard [...].

In addition to the shocking news, grandmothers suffered all along the course of the illness in face of the losses and suffering caused by it and its treatment. The suffering came when they realized they were mere witnesses of their grandchildren's suffering, unable to prevent it or do anything to stop the progression of cancer and its effects.

And I cried a lot, too... a lot... I cried to see her losing her abilities [...] to walk, to hold her head high, and her ability to swallow [...], it was the hardest part for me [...] when she smelled the smell of cake and cried, because she couldn't swallow...

Suffering multiplied — and muted

During the entire experience, the grandmothers' suffering was evident and very intense. They also taught us that this suffering is multiplied.

At first, the grandmothers' suffering seemed to be two-fold: in addition to seeing and suffering for the sick children, they also suffered to see the children's parents having to go through such a painful experience. However, if the sick child had a

sibling, the suffering was increased more because grandmothers also worried about and suffered for seeing their other grandchildren suffering for their sibling and the consequences of the illness on their lives.

And they told them (the child's siblings)... gosh, when we heard the siblings crying, we heard... it was also hard [...]. Our other grandchildren suffered for that [...] it was terrible...

Additionally to the grandmothers' suffering from witnessing the pain in other members of the family, they were also the protagonists of their own suffering, having somebody so dear to them sick, having their dreams and plans torn into pieces, realizing they are helpless before the advance of the illness. Therefore, the researchers understood that the grandmothers' suffering was immense, multiplied, and not equal to the sum of all the involved parties. They suffered for their sick grandchildren, the other grandchildren, their children, their families, and themselves.

The grandmothers perceived themselves as an important support being offered to parents, but they pointed out and legitimized their own pain, which, at times, did not find the space to be externalized. *What suffering can be greater than that of the parents?* — it is the question that mutes and sometimes isolates grandmothers in their multifaceted experience of pain, helplessness, and frustration.

Trying to gather strength to tolerate the intolerable — the muffled cry for support

There was great need for information on the part of the grandmothers; not having information brings about even more suffering and increases the sense of isolation and loneliness in their experience. The grandmothers, then, began to realize the need for support and, sometimes, thought about resorting to their own children to find it. However, afraid of adding to their children's overload, some of them chose not to share their narratives of suffering with them, believing that this way they would save them from even more suffering. Others, based on their belief that a close-knit family shares the burdens of one another, sought comfort from and helped the sick child's parents — and thus they found mutual help.

Be that as it may, the grandmothers' choice was to express and share their experiences and suffering only with people for whom they were sure this would not be a hindrance or even add to the emotional overload.

The decision to suppress their own feelings and not open up or share them with anyone also came from the belief that, at that moment, tolerating the suffering at any cost was their task. To them, their own pain came second; the first priority was to look after their grandchildren's families — and for that to happen, there was no room for suffering. Their intense suffering, experienced in darkness, blew up in silence, causing emotional consequences in the grandmothers.

I think grandparents [...] I can't speak for all, but with me it was like this: we suffer but I don't know; as grandmothers we always try to swallow everything, to really swallow,

then we'll see, but now I need to swallow everything to give them strength... this was what I thought...

For other grandmothers, the expression and sharing of the suffering within the family communicated empathy, the capacity to feel other people's pain, an act of care in itself.

I think it's important for grandparents not to play the role of being strong in the family [...]. I think the family needs to feel that you also feel it! Some people go like: oh, no, I need to be strong, but what is this? Stifling your own feelings, not letting your children know you are suffering because your grandchildren is sick?

The grandmothers often took the responsibility for difficult moments in caregiving and treatment in the place of the parents, increasing the distress and intensity of their quiet suffering. At moments when parents were too burned out or physically and emotionally shaken to make decisions regarding their children, the grandmothers were called on to take the responsibility, decide on treatments, agree to invasive procedures, and even keep company with their grandchildren. The grandmothers did not see any other choice than taking up this role, swallowing and suppressing their own pain.

If I thought about her, I cried. Being responsible for agreeing to the amputation surgery on her finger was too much for me. But I had to do it because her parents had no (emotional) condition to do so. And who said I did? But I had to take that on me. It was too much for me. But when the time comes... we do it.

Always present... behind the scenes — grandmothers' role

Even in face of all this suffering, the grandmothers did not hesitate to help. All the participants of this study recalled important changes in their routines and daily lives with the emergence of the cancer and during its treatment. It was as if their own lives were put in second plane. Although it cost a lot from them, they did not envision any alternative but to give up their own needs to be close to their children and grandchildren.

The grandmothers were always available to provide practical, instrumental, financial, and emotional support that their children's families needed to accommodate the new demands posed by the illness. They took upon themselves the role of coordinating their children's households and all of their families' demands, so that they could concentrate on looking after the sick child.

I did everything in the house, with the other children... we did all that was possible so that J (daughter) could look after E (sick granddaughter) peacefully. I was more in charge of the technical part (laughter), helped with bathing, took care of the food, of cleaning [...]. I controlled the house!

The grandmothers' entire support and presence was, in their own perspective, welcome and necessary to the families. Nevertheless, the grandmothers learned that there are some boundaries they must respect as grandmothers so that the relationship would not become conflicting. The grandmothers

had to recognize and understand the sick children's parents' independence and self-determination, respecting their decisions and autonomy, balancing their advice and desire to be always present.

This is why we talk about an important role that is performed behind the scenes: because what can be learned from them is that, in the battle against cancer, the grandmothers kept supporting in whatever way possible and necessary, often being the strength that supported the rest of the family, but they needed to understand and respect the fact that the greatest responsibility lay on the parents. They are on the forefront.

However, acting behind the scenes could be a source of additional suffering to the grandmothers because it was a position where control was in someone else's hands. The responsibility for decision making was someone else's. When the grandchildren were sick, not being responsible for them and being always present were difficult roles to reconcile; yet, even while suffering, they understood that this was their role and tried to accept it in order to preserve the relationship between generations.

But to me it was very hard because of what I told you: she was kind of like my daughter, she spent the day with me, I took her to the pediatrician! Think about it! Then there's that, too: suddenly she gets sick and I can't take her anywhere any longer, now her mother does it. I took care of everything before that and now that I wanted to be more present, I couldn't...

A new way to see, to be in the family

Seeing how their children dealt with their own children's illness made the grandmothers rethink and reflect on them as adults. In almost all of the interviews, the interviewees mentioned their pride in their children's maturity. They observed their children's attitudes, poise, and decisions and felt glad to see them reacting to such a painful situation. At times, this brought relief and comfort to their multiplied suffering.

And J, my daughter, you must meet her, she's a really strong woman, [...] she was a true lawyer for E at her school, for her treatments, and... I mean... she was, and she still is, a very strong woman, very determined and capable. God knows who He can give this type of problem to!

The intensity of the experience lived inevitably called for a reflection: who are they as individuals and also as grandparents? "I am a different grandmother now" was a recurrent statement among participants of this study.

There were many possibilities for transformation, but their intention was the same: to remain closer to their grandchildren and more active and participative in their children's lives. The bonds and interactions that grew stronger with the illness were perceived by grandmothers as precious, and they fought to keep this union. With that, they sought to help their children and themselves.

The grandmothers, then, wanted to intensely enjoy each moment they spent with their grandchildren because, with the experience of cancer, they learned that there was possibility that they would go away before they did.

Now, I want to be present. I want to go to the parties, I want to see them whenever I can because we usually think children last forever, you know? Or at least they will bury us. And suddenly you see that it's not like that...

“There is always something in the air” — fear that remains

The grandmothers transformed and gave new meaning to their lives, awakening very intense feelings in their daily lives. From one perspective, the good moments are lived with much greater emotion and intensity because they look at their grandchildren, remember their illness, and feel grateful for it being under control and happy about the children's survival.

By contrast, these intense feelings are also present in a negative way. Ordinary moments in life, such as seeing the grandchild who had had cancer—or any other grandchild—cough, have a fever, or show other symptoms become very frightening because the grandmothers remember the cancer and feel terrified when thinking that these symptoms may be indications of its return.

I always think about the illness. Oh, will it come back, this kind of thing... I get desperate, she can't get anything! She can't cough close to me 'cause I get desperate. Not just her, the other grandsons, too! I've always been a bit like this, but after the illness I got even worse.

The fear that the illness will come back and break into the grandchildren's and their families' lives remains the same even many years after the treatment finishes. Periodic check-ups, which are necessary, always cause fear and concern. As children grow and their checkup examinations remain negative, the fear seems to be camouflaged among the ordinary aspects that life shows again. Nonetheless, even though they say the worst phase is already behind them, vigilance and the feeling that “there is something in the air” remains. The grandparents' peace is constantly threatened.

After the fright is gone, I think we almost forget about it. We're always monitoring it but it's no longer that crazy thing that happened during the treatment... but, you know... I think that with this illness, we will never feel really peaceful.

DISCUSSION

The value and usefulness of social and human research lies in the ways through which the understanding of a particular experience can bring about practical changes. Thus, we believe that this study's understanding grandmothers' experience in face of their grandchildren's cancers can provide material for reflection, new guidelines to health care professionals' actions, and a foundation for new research.

Grandmothers' suffering is intense and pervades all the stages of their experience. Learning about their grandchildren's cancer is overwhelming. Testimonies from other cultures are similar, restating the emotional load that is deposited on grandmothers at the moment of their grandchildren's diagnosis^(9,16-17). When reading studies that dealt with parents' experiences in face of their children's cancer, one can infer

that grandmothers' feelings equal those described by parents themselves⁽²⁻³⁾.

Studies have shown grandmothers' experience regarding their grandchildren's illness as two-fold or even three-fold suffering^(8,16-17). In this study, the grandmothers described their suffering in terms of their grandchildren, their children, and even their healthy grandsons. However, this study shows that this suffering goes beyond the sum of experiences; rather, it is multiplied: they suffer for their grandchildren, children, healthy grandchildren, and themselves.

And they suffer in silence. The dimension of grandmothers' suffering in the face of a grandchild's illness and death is often muffled by multiple factors, among which are their desire and disposition to suppress their own emotions and to seem strong for their children, and the scarcity in resources and specific sources of support for this population⁽¹⁶⁻¹⁷⁾.

Findings like these, which highlight the isolation in grandmothers' experiences, are found in various contexts and cultures^(4,7,10). Grandparents seem to tolerate the intolerable because they see it as the single alternative they have to be present for their families: to be strong or to seem strong so that they are able to help.

Nevertheless, this emotional overload, when intense and silenced, has clear consequences on grandmothers. A recent study that investigated the prevalence of stress in 221 grandmothers (87 grandmothers of children with cancer and 134 in the control group) found that grandmothers of children with cancer are significantly more exposed to stress and more prone to develop depression and other psychiatric symptoms⁽¹⁸⁾.

The same study also pointed out that less than 5% of grandmothers have access to psychosocial support groups, both in the control group and in the group of children with cancer. The study concluded that grandmothers' ability to be an important social resource for their families can be harmed by their own stress not being treated and assessed adequately.

Having little or no access to resources that support grandmothers is a circumstance that has also been found in this study; this points to a need for changes. Before all the suffering disclosed, it is not possible to disregard grandmothers in nursing care plans and actions.

Support programs aimed at grandmothers of children with cancer and other serious illnesses have been established in countries such as Australia, Canada, and the United States and resulted in reduced anxiety, more self-confidence, and more security to live with and care for their sick grandchildren^(16,18-20). However, although these groups are an important, valid strategy, one must take into account that many people do not feel comfortable sharing their own experiences and may refuse to participate, even though they want help⁽¹⁷⁾.

One form of support network that has been growing in all areas and can be considered viable and recommended to grandmothers is virtual social networks, such as Facebook, Twitter, etc. The use of computers, smartphones, and tablets is increasing, especially among grandparents. A recent news article in a renowned Brazilian paper claims that in 2013, people above 65 years of age were the fastest-growing sector

in social networks in the United States, reaching 45% of those who surfed the Internet at this age⁽²¹⁾.

One cannot deny that this tool can be a valuable therapeutic strategy to reach grandmothers who are more resistant or cannot attend support groups. There is already evidence of the importance of virtual social networks in finding support for illness and grieving situations⁽²²⁾.

Another demand raised by grandmothers in this study was information. Thinking about the family is a challenge that must transcend our prejudices and predefinitions of nuclear families and must include grandparents, usually such an important source of support, and turn the attention of professional staff to the occasional doubts and gaps of knowledge that they may have concerning the children's illnesses.

An Australian study pointed out that grandparents of children with cancer want more information to feel secure, so that they no longer depend on "second-hand" information gotten only through the children's parents and are able to be more effective in the support they give to their families. Thus, they consider that the development and application of a form specifically designed to identify grandparents' information needs may help the team in assessing them; therefore, they can find ways to provide them with that information and help families fight cancer⁽¹⁸⁻¹⁹⁾. This is of great importance, and the authors of this study recommend new research in this area in order to identify and understand this population's information needs and learn how to intervene.

After finishing treatment, the families of the surviving children try to live in a way that can recover the normal conditions that existed before the illness came into their lives, but the fear remains. The feeling that the grandmothers who participated in this study described as "there is always something in the air" is similar to descriptions given by juvenile cancer survivors in a national study⁽²³⁾. In that study, survivors described their experiences of surviving cancer as being able to enjoy a perception that they were free from the illness, but having to maintain their care for their health, which they could not neglect. The certainty that the illness has been absent for years is threatened in each examination. Even many years after the end of the treatment, just like the grandmothers described in this study, they still say they are afraid the cancer will come back and are worried about the effect of the treatment on their grandchildren.

The permanent tension in face of the possibility of relapse illustrates the feeling of insecurity among grandparents even many years after the treatment is finished. There is a struggle to leave behind what was lived and to focus on the present

moment, but the load of suffering experienced by grandparents is such that the memories from their past often threaten their peace of mind. That being the case, in addition to being imperative that health care professionals approach families' third generation and include them in their care during the diagnosis and treatment phases, it is necessary to follow up continuously even years after the end of the treatment.

The novelty in the scope of this research demonstrates the advance that its results bring about. The goals reached enabled the realization of the need to advance even more in research on this subject. It was observed that the third generation of families that have a child with cancer needs support, attention, and care.

The absence of male participants in this study brought about a very singular aspect to the interviews and experiences, limiting the data of this study to grandmothers. The authors recommend conducting new studies that seek to understand the impact of this experience on grandfathers and on couples.

The authors highlight the possibility of including grandmothers in projects and public policies that promote active participation by family members in the hospitalization of children. The benefits of including parents in the hospital are already well known. The authors of this study believe that including grandparents as part of care, including encouraging their presence in the hospital environment, can be an additional factor that will produce good results for children's health and for the grandparents themselves.

FINAL CONSIDERATIONS

This research has given a voice to a kind of suffering that is immense yet very little known and little discussed in our culture: the suffering of grandparents. It was observed that the third generation of families that have a child with cancer needs support, attention, and care.

Given grandmothers' experience, it is clear that there is a need to review our definitions of family, to redefine the concepts of family-centered care, and to extend our actions to those members who are increasingly active and participative in family issues, including illnesses.

Therefore, this study's results can foster a deeper understanding of the effects of children with cancer on families, focusing on grandmothers. It can also raise nurses' awareness about the need to consider and develop strategies of family assessment and intervention with the goal of minimizing grandparents' suffering.

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