

THE GRANDPARENTS OF SICK CHILDREN: A NEW PERSPECTIVE FOR RESEARCH WITH FAMILIES IN BRAZIL

OS AVÓS DE CRIANÇAS DOENTES: NOVA PERSPECTIVA PARA PESQUISAS COM FAMÍLIAS NO BRASIL

LOS ABUELOS DE NIÑOS ENFERMOS: UNA NUEVA PERSPECTIVA PARA LA INVESTIGACIÓN CON FAMILIAS EN BRASIL

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ABSTRACT

Due to the global aging phenomenon, the possibilities of three or more generations coexisting in the family has significantly increased. Thus, the bonds between grandparents and grandchildren have also become stronger. Brazilian literature already indicates the influence of the relationship and the presence of the third generation in the family in daily contexts, but only two studies actually address the situation of the grandchild's disease. The aim of this study was to formulate a few considerations on the matter, grounded in recent literature that addresses the impact and experience of the grandchild's disease on grandparents and their role when their grandchild is sick. From this, we design paths and perspectives for new Brazilian studies focusing on the grandparents when one of their grandchildren is sick. We believe it is important to advance in this area in order to promote the comprehensive care of children and family based on scientific evidence.

Keywords: Pediatric Nursing; Family; Aging; Family Relations.

RESUMO

Diante do fenômeno do envelhecimento global, aumentaram-se as chances de três ou mais gerações coexistirem na família. Com isso, os vínculos entre avós e netos também têm se tornado mais fortes e duradouros. A literatura nacional já registra a influência do relacionamento e presença da terceira geração na família em contextos cotidianos, mas apenas dois estudos são encontrados na situação de doença do neto. Buscou-se neste trabalho tecer considerações sobre o tema, respaldadas em publicações recentes, abordando o impacto e a experiência da doença do neto para os avós e o seu papel quando um neto está doente. A partir disso, traçaram-se caminhos e perspectivas para novas pesquisas brasileiras que tenham o foco na figura dos avós na situação de doença do neto. Acredita-se ser importante o avanço nessa área, de forma a promover o cuidado integral à criança e família baseado em sólida fundamentação científica.

Palavras-chave: Enfermagem Pediátrica; Família; Envelhecimento; Relações Familiares.

RESUMEN

Las probabilidades de que tres o más generaciones convivan en familia han aumentado ante el fenómeno del envejecimiento global. Con ello, los lazos entre abuelos y nietos también se han vuelto más fuertes y duraderos. La literatura brasileña ya señala la influencia de la relación y la presencia de la tercera generación en la familia en contextos cotidianos, pero sólo se han encontrado dos estudios que enfocan una situación de enfermedad de un nieto. En este trabajo se busca establecer consideraciones sobre el tema, respaldadas en publicaciones recientes, que traten del impacto y la experiencia de la enfermedad del nieto para los abuelos y de su rol cuando un nieto está enfermo. A partir de ello, se han trazado caminos y perspectivas para nuevos estudios brasileños que se centren en la figura de los abuelos cuando uno de los nietos está enfermo. Creemos que los avances en esta área son importantes con miras a promover la atención integral del niño y de la familia sobre bases científicas sólidas.

Palabras clave: Enfermería Pediátrica; Familia; Envejecimiento; Relaciones Familiares.

INTRODUCTION

In Brazil and the world today, we are witnessing the phenomenon of an increase in human longevity. In 2000, the expectation of life for Brazilians was 68 years; in 2011, data from the Brazilian Institute of Geography and Statistics (IBGE) indicated that this number had risen to 73. With this, society has also been undergoing a transformation in the realm of family relationships, especially concerning intergenerational relationships. Grandparents are becoming grandparents earlier and are experiencing this role for longer. Today, they are considered “able”, that is, at an appropriate or more common age to play this role, upon becoming grandparents for the first time between 39 and 60 years of age. Early grandparents are those who have grandchildren before they turn 38 years of age.¹ In the United States, nearly 50% of the people become grandparents between 49 and 53 years of age. In France, it is estimated that 80% of the grandparents are over 65, and of these, 50% have already become great-grandparents. In England: 50% of the grandparents are under 65.² This scenario exemplifies the fact that today the probability of three or even four generations coexisting in the family is high.

In addition, with the increase in the divorce rate, the insertion of the woman in the work field, the growing index of single parents and, in Brazil, the high cost of elementary school, what has arisen is the increase in the importance of the grandparents in the family nucleus. They, now much younger, have become more active and participative within families. Studies indicate that the grandparents are the main alternative and reliable option for the mothers so they can carry out professional and personal activities.¹⁻³

With a more active participation, the affective and relational involvement with the grandchildren is inevitable and even more intense, which leads to positive consequences for the entire family, but can also bring conflicts if there is not an open communication concerning the roles and limits of the grandparents in the family.¹⁻³

Research in Brazil already recognizes the role and influence of the grandparents in the family and the transformation in the relationship between the grandparents and the grandchildren, as well as between the grandparents and their adult children, proving just how important this relationship is and how it can determine changes and directioning in the family's daily routine.

In situations of transition of the family's life cycle, such as the maternity of the daughters and/or daughters-in-law, the grandparents exert an important influence and these have been the elements of greatest interest to researchers in our present-day healthcare literature.⁴⁻⁶

One recent study investigated the importance of intergenerational relationships in the family of a child with special needs. In this study, the authors found that the families in this context count on the grandparents as a key source of support

and that these grandparents put off or abandon plans (e.g. trips, retirement) so that they can wholly dedicate themselves to their child's family. The authors even report having found triple concerns on the part of the grandparents – with their son/daughter, with the sick grandchild, and with the healthy siblings – and that, in general, the feelings regarding their grandchild's condition of special needs are similar to those of the parents themselves, but with less possibility of being shared, divided, and, consequently, cared for.⁷

The aforementioned data have yet to be published in the Brazilian context, having found only one such article to date that had evaluated the experience of the grandparents when one of their children is ill.⁸ In this last case, the suffering of the grandparents is evident and underscores the need for further investigation, which has been scarce in contexts of disease in Brazil. The authors emphasize that the grandparents were not heard or considered part of the patient's professional care, even in contexts centered around the child and the family.

Faced with the evidence found in Brazilian literature, one can perceive the importance of the grandparents' role in the family and the impact that the intergenerational relationships can have on the family dynamic in common everyday situations, but the movement of Brazilian researchers to investigate these relationships in the context of disease is still rather weak.

Nevertheless, international literature on the issue has already published a number of studies that have the grandparents not only as the focus, but also as subjects of the research, and within the realm of disease or hospitalization of one of their grandchildren.

Hence, the present article aims to stimulate and encourage the development of Brazilian studies from this new perspective: intergenerational relationships when a child is ill. This is a reflective essay, constructed from recent scientific literature, aimed at providing material to better understand this theme, as well as to generate new questions and research perspectives for the Brazilian society.

THE IMPACT AND THE EXPERIENCE OF THE GRANDCHILD'S DISEASE FOR THE GRANDPARENTS

When faced with a severe illness, the grandparents describe their feeling in a manner similar to that of the parents themselves: shock, anguish, profound sadness, and fear are a few of the examples of the reported reactions.⁹ For them, seeing their grandchild ill goes against everything they imagined and dreamed of for their grandparent lives, and the dream of being a grandparent is often shattered by the diagnosis.

The literature describes the experience of the grandparents in this context as ‘doubled suffering’: they not only suffer

for their grandchild, but also for their child, who they see passing through such a painful situation.⁹⁻¹¹ One study broadened this description to a 'tripled suffering', since, in addition to the aforementioned elements, the grandparents also suffer upon seeing their other grandchildren – healthy siblings – being inevitably affected by the experience.¹²

Despite such a heavy emotional load being deposited upon them in such situations, there is evidence in American studies that the grandparents believe that they should hold their own feelings back. Thus, they believe that they are helping their adult child's family, since they do not become an additional burden and, upon suppressing their own emotions, they hope to present themselves as more available and strong enough to provide support to their children.^{9,11}

However, this attitude often comes at a high price, as the grandparents are unable to find other sources of support or means through which to express their own feelings, which unleashes physical and emotional problems.

One recent study, which investigated the prevalence of stress in 221 grandmothers, with 87 grandmothers of children with cancer and 134 controls, found that the grandmothers of children with cancer are significantly more exposed to stress and are more prone to developing depression and other psychological symptoms.¹³

Among the grandparents' needs, information and inclusion are the most critical. The grandparents receive information on the state of health of their grandchildren, primarily through their children, but feel dissatisfied for not being considered part of the immediate family by the medical professionals to such a degree that they would be included in the sharing of medical information. The grandparents would like to receive information on the health of the grandchild from the healthcare staff itself and have direct access to them for the clarification of doubts that, many times, they have but their children do not.^{10,11}

Even if they are caretakers or switch on and off with the parents during hospitalization, the grandparents perceive that the staff often wait for the parents to arrive to pass on information or convey specific information to the grandparents quickly and superficially, waiting for the parents to arrive to then give the full report. They therefore feel neglected and pushed aside by the medical staff, which increases their suffering and feeling of isolation.^{9-12,14}

THE ROLE OF THE GRANDPARENTS WHEN ONE OF THEIR GRANDCHILDREN IS SICK

When faced with their grandchild's illness, the grandparents, investigated in different cultures and contexts, indicate

that they believe that their main role is to be present to meet the needs of their child's family.^{10-12,14,15}

The grandparents do not hesitate to offer help. Upon being asked about their experience, they often remember important changes in their own daily routines with the notification of the illness and during its treatment.^{12,15} It is as if their own lives were put on a second tier. They make themselves available to give all practical, instrumental, financial, and emotional support that their child's family may need to deal with the new demands resulting from the illness. They take it upon themselves to coordinate their child's household and all the demands of their family so that they can concentrate on caring for their ill child.

As a part of this role, the grandparents cancel or put off plans that they had made for themselves and begin to give unconditional support to their child.^{11,15} They assume the responsibility of caring for other grandchildren so that their children can fully dedicate themselves to their sick children and seek to maintain the family life flowing as normally as possible. One study indicated, as an encumbrance of the grandparents, maintaining the family united, that is, being the tie between what happens inside and outside of the hospital and maintaining a balance, especially so that the sick grandchild and the healthy grandchildren receive the due attention from their parents.¹⁴

In addition, some studies have indicated that the grandparents take it upon themselves to face the difficult task of listening to the reports of suffering from their children and their spouses, who are passing through the experience of having a sick child.^{9,10,14,15} This task is, often times, a heavy burden for the grandparents, given that it increases in them the feelings of impotence and anguish in the face of their grandchild's illness. Moreover, the aforementioned lack of support lines for the grandparents, together with the burden of hearing the suffering of their own children, leads them to suffering and isolation in their own experience.

All the help, presence, and support provided by the grandparents seems to be well-received and necessary for the family.^{10-12,14,15} Nevertheless, there is still a challenge for the grandparents, who, as such, must recognize that there are limits and that these limits should be observed to prevent conflict within the relationship. They recognize the importance of understanding the independence and self-determination of the parents of the sick child, respecting their decisions and autonomy, balancing this with advice and their own desire to be present at all times.^{10,14,15} The grandparents continue to support, in that which is possible and necessary, many times even becoming the backbone of the rest of the family. However, they must understand and respect that the greater responsibility, and who will take the lead, lies in the parents' hands. Anything to the contrary, and additional conflicts and suffering will be inevitable.

CONCLUDING REMARKS: NEW DIRECTIONS FOR RESEARCH IN BRAZIL

Faced with that presented above, in which an overview of what has been investigated with the population both inside and outside of Brazil, it can be concluded that the grandparents lack the due attention from healthcare researchers.

Studies that have focused on the grandparents as the core subjects and focus of research, in different contexts of their grandchildren's disease, are encouraged so as to broaden the knowledge surrounding the range of feelings and emotions lived by them. In addition, qualitative studies with this focus will also aid the researcher in better understanding what the true needs of this population are and what type of resource network is available – or not – to them to confront this situation.

The family relationships of the grandparents also deserve investigation. How were the relationships before and after the disease, in what way have they been modified? Relationships with the sick child's parents, with their siblings, with the healthy and the sick grandchildren, in what manner do they act during and after the disease? How does the relationship proceed between the grandparents when the grandchild is sick?

The literature presented in this study clearly indicated that the grandparents still do not feel that they are considered part of the family by the medical professionals and that they do not truly appreciate their recognition of their own suffering when experiencing their grandchild's illness. Hence, studies that evaluate the perspective of healthcare professionals as regards the participation and inclusion of the grandparents is warranted, since a new way of thinking about the family must impact the interdisciplinary team so that the medical care is also broadened and offered to the grandparents.

It is important to emphasize that, much like the renowned Canadian researchers on the family, it is not the intention of this text to "romanticize" the figure of the grandparents;¹¹ the literature itself indicates the presence and possibility of conflict that can exist within the family, both inside and outside of crisis situations.

Nonetheless, the body of scientific evidence that reflects the influence and the impact of the grandparents needs to be

considered by the professionals, as does the impact of the grandparents' experience. Through these measures and progress in research, it thus becomes possible to think about this issue in Brazil as well, through interventions and even public policies geared toward the grandparents in such a way as to minimize their suffering and promote a more complete attention to healthcare.

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