

# Grandparents: A hardly recognized part of the childhood cancer family

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In this issue of *Pediatric Blood and Cancer*, Wakefield et al. present the data on the quality of life, medication and hospitalizations of the grandparents of children with cancer.

Often grandparents play an important role of providing emotional and practical support for families affected by childhood cancer. Many of them try to support the families by taking over childcare duties for the siblings or spending time in the hospital or at the outpatient appointments to give the parents a break or even providing financial support. These emotional and physical duties can clearly affect the quality of life in this population with potentially pre-existing health problems.

As we know, childhood cancer affects the whole family, and this study specifically addresses this issue for the grandparents. Grandparents of children affected by cancer were assessed regarding their quality of life including anxiety or depression, as well as sleeping patterns, use of medication, and need for hospitalizations. These findings were compared with those from a nonaffected control group and clearly demonstrated a worse quality of life in the affected grandparents, with a higher rate of anxiety and depression as well as problems falling asleep. Grandparents often have a "double worry": they are worried about their child as well as their grandchild. Especially grandmothers seem to worry more, which affects their quality of life.

The same group had previously studied grandparents of children with cancer, focusing on distress, support, and barriers to care.<sup>1</sup> Distress, anxiety, depression, and anger were at high, clinically relevant levels compared with those in a nonaffected control group; again, grandmothers showed a higher distress level. Grandparents do occasionally seek psychosocial support, but more of religious/spiritual support. Barriers to seeking care seemed to be the lack of knowledge and rurality.

So, do we need to extend our family-centered care in pediatric oncology to grandparents to stabilize the family system and enhance support within the family?

So far, only limited data are available on this topic. A recent study from Brazil investigated the grandmother's experience of a grandchild with cancer via interviews.<sup>2</sup> The main topic was suffering—multiplied,

silent, and permanent. Grandmothers see their role as being present and supportive to their children and grandchildren, but they balance this with accepting their adult children's independence. So far, suffering experienced by grandmothers has not been recognized by the healthcare system.

A similar study was done in Canada a few years earlier.<sup>3</sup> Grandparents were interviewed and they shared their experience of having a grandchild with cancer. The main topics were again worry and suffering: "double worry" about their children and grandchildren and silent suffering to minimize the burden for their adult children. Their experiences with the healthcare team were not always positive due to neglect. Overall acknowledgment, recognition, and inclusion by the healthcare team are very important issues for grandparents.

So, given these concerning, but not unexpected, findings, what can the healthcare system do to support and better care for grandparents of children with cancer?

One step could be to better inform the grandparents about their grandchild's disease to decrease their stress level. Grandparents often get their information second-hand via the parents and do not want to burden the parents with their own questions and anxiety. Wakefield and her group have created and implemented a questionnaire to measure the information needs<sup>4</sup> and, based on these findings, an information booklet.<sup>5</sup> Grandparents are most interested in the chances of survival as well as possible consequences of the cancer and treatment. An information booklet addressing these questions was created to inform the grandparents first-hand and evaluated by the grandparents as very relevant for their needs.

Further aspects of support were investigated by the Canadian group of Moules et al.<sup>6</sup> as part of their interviews with the affected grandparents. Support groups or online forums were suggested as places to talk and share experiences with people in a similar situation. System awareness as family-centered care could be another means of support. Again, information about their grandchild's disease was recognized as the most important support, provided either by a brochure or by direct communication to get their questions answered.

Pediatric oncology care is a family-centered care and so far grandparents have been an underrecognized part of the family. The health-care team has to acknowledge the distress of the grandparents and support and inform them as for all other family member.

#### CONFLICT OF INTEREST

The author declares that there is no conflict of interest.

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