

04/09/2017

The invisible patients at onco-hematological pediatric units



After a child recovers from cancer, the emotional distress caused by the experience significantly affects 34% of parents, according to this study, carried out by researchers at the UAB and the VHIR. The authors have analysed the causes behind this negative emotional state by interviewing the mothers and fathers of these children. They suggest establishing prevention strategies to reduce its occurrence and treatments to alleviate or prevent its cronification.

Image: Sisyphers by Tomasz Moczek (from Picdrome)

Pediatric oncology professionals usually focus their efforts on working for the survival and health-related quality of children suffering from cancer. Despite these professionals being in close contact with the patients' relatives, sometimes they could overlook that a cancer diagnosis always succeeds in a concrete family environment.

Home discharge once cancer enters into remission is usually experienced as a remarkable moment to celebrate with joy; however, it is not infrequent that when specifically asking about concerns related exclusively to cancer, parents recognize that they still feel certain emotional distress due to fears of recurrence and concerns related to the future of their children. In this sense, some studies have revealed that the experience of parents with offspring suffering from cancer could be characterized by high levels of emotional distress that might persist throughout

the remission and cancer survival period (Bruce 2016; Manne, 2005). It is uncertain which variables present during the phase of hospitalization and active treatment could modulate this emotional distress. Notwithstanding, it is well known that if this distress persists and becomes chronic, it might lead to serious consequences hampering well-being and health-related quality of the whole family. Therefore, screening procedures and adequate therapeutic approaches are necessary.

Parents showing good adjustment to their child's cancer remission situation will be able to establish appropriate psychosocial connections (i.e., with other relatives, with school, friends, etc.) and then, they will become a better supportive resource for their children, so recovery of the minor and successive resolution of day-to-day problems will be more effective and satisfactory. On the other hand, parents who are stressed and emotionally unwell will hardly be able to deal effectively with challenging and problematic situations, since they themselves have not been able to normalize their situation in survival.

Thus, it is necessary to know in greater detail what elements of the experience of the disease seem to produce the persistence of that emotional distress at the time of oncologic remission, and why other parents do not manifest such distress, or do it to a lesser extent. This knowledge will be of great help in designing preventive interventions that favor a more adequate and early management of this problem.

Methodology and results of the study

To approach this reality, we interviewed 41 parents of pediatric survivors of different types of childhood cancer (excluding central nervous system cancer due to the idiosyncrasy of these patients). We assess aspects such as perceived social support, optimism or coping in the worst moments of the disease and also, general stress, emotional distress in relation to cancer and positive and negative consequences related to and in the aftermath of cancer.

The results indicate that a high percentage of parents (34.1%) affirmed that they still felt quite a lot, a lot, and a high amount of distress in survivorship period. When studying this distress, it was observed that it was related to having received less social support during the hospitalization, using an evasive coping or avoiding the problem, and feeling that they had to make more efforts to deal with difficult situations during the active phase of cancer treatment. Despite this, 22% of the parents said they had been able to yield some kind of positive consequences in survival. In addition, 60% of them claimed to have had both positive and negative consequences.

Conclusions and clinical implications

Results suggest that the end of the treatment is not exactly "the end" of everything lived for the parents of a child who has had cancer. Contrary to what might be expected, in the survival stage, a significant emotional distress persists in a high percentage of parents that does not seem to be determined by the sequelae that the child may present after the diagnosis and treatment of cancer, or by other variables such as age at diagnosis or time elapsed since then. In addition, this emotional discomfort is not incompatible with the occurrence of positive consequences of the experience lived.

These results suggest the pertinence of screening strategies and psychological counseling to

parents during the phases of treatment and hospitalization of the child. The ultimate goal would be to offer psychotherapeutic measures and personalized psycho-educational interventions that can alleviate such discomfort and/or decrease their probability of occurrence or chronification.

This work has been developed based on Dr. Castellano-Tejedor PhD dissertation data and partly funded by the grant (FPI00286) 2007-2011 and Ministeri Ciència i Innovació PSI2008-06417-C03- 01 / PSIC financial support..

Carmina Castellano Tejedor

ninacastej@yahoo.es

Vall d'Hebron Research Institute (VHIR)

Department of Basic, Developmental and Educational Psychology

Universitat Autònoma de Barcelona

Tomás Blasco Blasco

Tomas.Blasco@uab.cat

Department of Basic, Developmental and Educational Psychology

Universitat Autònoma de Barcelona

References

Original reference:

Castellano-Tejedor C, Blasco-Blasco T, Pérez-Campdepadrós M, Capdevila L. [The Hidden Sufferers: Parental Reactions to Childhood Cancer during Treatment and at Survival.](#) *Span J Psychol*, 2017;20:E29. <http://dx.doi.org/doi: 10.1017/sjp.2017.26>.

Other references:

Bruce M. A systematic and conceptual review of posttraumatic stress in childhood cancer survivors and their parents. *Clin Psychol Rev*, 2006;26(3):233-256. <http://dx.doi.org/10.1016/j.cpr.2005.10.002>

Manne S. Our invisible patients. *J Clin Oncol*, 2005;23(39):7375-7377. <http://dx.doi.org/10.1200/JCO.2005.07.905>

[View low-bandwidth version](#)