

Children of cancer patients are too often excluded from the disease journey, research shows

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The announcement of a cancer diagnosis abruptly and durably alters the course of daily life—not just for the person receiving it, but also for their family. New research presented at the [ESMO Congress 2021](#) suggests that adequate communication and support for children of cancer patients still represents a significant unmet need that parents require help to fulfill.

In 2020, an estimated 4.6 million individuals aged 20 to 54 years were diagnosed with the [disease](#) at a time of their lives when they are most likely to be raising [children](#). The impact of parental cancer on a child's development varies according to the child's age and the evolution of the illness, but also, crucially, depending on how the child has been included in the parent's disease journey.

Giving bad news to their children and addressing the distress this may cause them is one of the most daunting tasks that [parents](#) face at a time when they must process their own emotions about the disease. Yet according to Prof. Carlo Alfredo Clerici, a clinical and child psychology expert from University of Milan, Italy, not involved in the study, "Current psychological perspectives see a certain degree of information to children about their parents' disease, and about the possibility of their death, as useful and protective against traumatic phenomena."

Ignorance is not bliss when a parent has cancer

The social and cultural resistance that often stands in the way of this type of dialog with children is evident from the results of a survey of 103 patients in Tunisia, almost 90% of whom reported communication disorders on the subject of the parent's illness and more than 40% choosing not to disclose the whole truth about their disease. According to study author Dr. Sinen Korbi, Institute Salah Azaiez, Tunis, the idea is widespread among patients that they are protecting their children's psychosocial equilibrium by shielding them from the reality of the illness: "This was cited as a concern by seven of the 18 parents in our study who chose to conceal the truth from their children entirely," he reported, adding that these represent missed opportunities to give hope to children at a time when, even in Tunisia where many cancers are diagnosed at an advanced stage, people do recover from the disease.

Almost all study participants (96%) observed behavioral changes in their children ranging from anxiety and depression, through academic difficulties all the way to violence and substance abuse—but only nine parents consulted a child psychiatrist. "Many people think they can handle these issues on their own or with help from relatives, but they need to be encouraged to report these problems to us so we can refer them to specialists if needed: this can be as simple as asking patients how their children are doing every time we see them," said Korbi.

"This study makes clear the need to increase knowledge about the role of psychological and emotional dimensions in people's lives. Efforts should be made to better understand and take into account, in a way that is compatible with social and cultural perspectives, the fact that children build their own interpretation of life and that they can suffer significantly when they do not have adults helping them to stay in contact with reality," said Clerici. "Future research should also aim to capture traumatic phenomena that unfold over time and which are associated with more worrying long-term consequences than the individual symptoms of distress reported here."

Trauma becomes particularly likely when a child is confronted with a parent's death from cancer. Communication with children about the disease should be an ongoing process that, ideally, would begin shortly after the announcement of an incurable cancer diagnosis and include practical preparations for life after the parent has died. These key conversations should be addressed in an age-appropriate way, but parents, who need guidance from professionals, mostly navigate the experience on their own, while health and [social care professionals](#) are often unaware of the challenges faced during this period.

Distinguishing between how much it is possible to prepare a child for the loss of a parent to reduce traumatic phenomena and the extent to which this loss constitutes a suffering that words can neither prevent nor mitigate, Clerici underlined the importance of recognizing that the support needs of children are not limited to the terminal phase of the disease and early stages of bereavement. "Their entire growth path will be shaped by the challenge of finding in the surviving parent, in new social and emotional relationships, opportunities to make up for their loss," he said. "Activating care resources that ensure long-term psychological support and monitoring of the child could help these individuals face the challenges of existence without feeling emotional loneliness or abandonment and, while meeting modest reimbursements from health systems, has the potential to produce significant healthcare savings in the long term."

More information: Abstract 1489P_PR 'Tunisian children and adolescents coping with parental cancer' will be available as ePoster as of Thursday, 16 September at 08:30 CEST. *Annals of Oncology*, Volume 32, 2021 Supplement 5.

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