

Trust is key for the parents of children with rare diseases to live without anxiety

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UOC research analyses the role of parents who are caregivers in these families.
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The parents of children with rare diseases face exceptional circumstances which influence their role as parents. Sometimes, the role of caregivers is added to that of parents. On other occasions, especially with the most serious cases, the former becomes more prominent than the latter. There are also cases in which both roles coexist separately,

allowing them to be parents and caregivers in equal measure. However, whichever group they belong to, they need trust and to overcome fear in order to live their experience without overwhelming anxiety.

This is one of the findings of an open-access study published in the *International Journal of Environmental Research and Public Health*, in which the researchers from the UOC's PSINET group, Beni Gómez-Zúñiga, Modesta Pousada, from the Faculty of Psychology and Education Sciences of the Universitat Oberta de Catalunya (UOC), and Manuel Armayones, from the UOC's eHealth Center, and Rafael Pulido, from the Department of Education of the University of Almería, interviewed parents of children with [rare diseases](#).

The authors of the study explained that the situation experienced by the parents of these families means that they give themselves entirely to the task. Also, their children require so much time, attention, physical and emotional energy that the parents "have and perceive a much greater burden than that typically associated with raising children," explained Gómez-Zúñiga. There is therefore an alteration of the parental role, with behavior linked to being both parents and caregivers at the same time. It is possible to confront this role from a [psychological state](#) that the authors call "emotional strength," which allows them to live the experience without great anguish or uncertainty when there is trust.

"Trust allows them to confront the situation with a more positive outlook," said Dr. Gómez-Zúñiga, who explained that it is not just a question of trusting in the doctors, but also of trusting in your own strength, that you will have enough energy to confront [daily life](#), in the suitability of the treatment, in the adequacy of the resources available or in the effectiveness of the support received by other parents in similar circumstances. According to the results of the study, with this experience of trust it is more difficult for existential unease to take hold. "One mother told us: "It's hopeless," but another, who had managed to increase

her trust for various reasons, told us: "Things are going to be all right." That is the difference, and that is what will mark the experience of these mothers and fathers," said Manuel Armayones, another of the researchers on the study.

The diagnosis, a turning point

Achieving this trust which allows the role of parent/caregiver to be confronted without high levels of stress, fatigue, insecurity or uncertainty, which are signs of fear, tends to be the result of a long process. The authors of the study stated that in their research some parents used expressions like "a horrible experience," "you suffer an enormous personal strain" or "you feel insecure when making decisions," and this was the origin of what this study describes as "existential unease." However, the diagnosis tends to be a turning point in this experience.

"There's fear concerning the diagnosis. And fear feeds the existential unease, present in the initial phases of their children's disease, before the diagnosis and immediately afterwards," explained Dr. Pousada. "However, from then on, this anxiety can open up a path to relative stability, above all if we have an antidote to this anxiety, such as emotional strength," she said. The experience is thus perceived with less suffering, as if the burden were lesser. This is when the parents adapt to the role of parents and caregivers, "and their experience could be summarized in their own words: "I am sure that I can handle all this," or 'we are in the best hands'", said Gómez-Zúñiga.

As pointed out by the authors of the research, trust contributes to this emotional strength. Faith also helps, understood as finding a spiritual meaning to their experience as parents. The researchers observed that faith opens the door to hope, at the same time as providing the [emotional energy](#) required to "keep going" and not break down.

"We must bear in mind that faith goes beyond trust. Trust is a faith supported by evidence, whereas faith is a relatively blind [trust](#). It is faith understood, to a certain extent, as a search for meaning, an effort to accept and understand the reality of the disease and of the personal and family life situation caused by it," explained Pulido, who added that this search for meaning may or may not be due to certain religious beliefs.

The result is a reparative effect on the existential unease because the sensation of the caregivers that they have found a meaning to what they do "is positively related to their own search for this meaning. That is to say that the more they seek a meaning to their activity as caregivers in their life, the more they find it. And, the more they find it, the more well-being they experience in their role as caregivers," said Pulido, who indicated that two of the most essential feelings can be found behind this experience: fear and love.

"Our theory on how parents build their role identity is that it is the result of the (relative and self-perceived) success or failure on progressively overcoming fear through love. This process takes a long time and has a profound impact, and we therefore like to describe it as navigating between love and fear," said Pulido. He added that, although the role can be represented in very different ways, the healthiest for the parents and for their children "is that in which love has triumphed. Fear overpowers the [parents](#), but love empowers them."

More information: Beni Gómez-Zúñiga et al, The Role of Parent/Caregiver with Children Affected by Rare Diseases: Navigating between Love and Fear, *International Journal of Environmental Research and Public Health* (2021). [DOI: 10.3390/ijerph18073724](https://doi.org/10.3390/ijerph18073724)

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