

# Accompanying a sick son until their death: starting again without ever forgetting

Maria Eduarda Correia<sup>1</sup>

 [orcid.org/0000-0001-8322-4437](https://orcid.org/0000-0001-8322-4437)

Maria Teresa Magão<sup>2</sup>

 [orcid.org/0000-0003-0294-3590](https://orcid.org/0000-0003-0294-3590)

Maria Antónia Miranda Rebelo Botelho Alfaro Velez<sup>3</sup>

 [orcid.org/0000-0001-7356-2053](https://orcid.org/0000-0001-7356-2053)

<sup>1</sup>Escola Superior de Saúde - Instituto Politécnico de Portalegre, Portalegre. Centro de Investigação, Inovação e Desenvolvimento em Enfermagem de Lisboa (CIDNUR), Lisboa, Portugal.

<sup>2</sup> Escola Superior de Enfermagem de Lisboa, Lisboa. Centro de Investigação, Inovação e Desenvolvimento em Enfermagem de Lisboa (CIDNUR), Lisboa, Portugal.

<sup>3</sup> Escola Superior de Enfermagem de Lisboa, Lisboa, Portugal.

## Introduction

Parents who accompany their children with a complex chronic illness until their death experience a unique situation, with vulnerabilities and lived individually, with specific needs and enormous suffering.<sup>1</sup> This study sought to answer the research question "What is the lived experience of parents who accompanied their children with a complex chronic illness until their death, in a paediatric palliative care setting?"

## Objective

To describe the lived experience of parents who accompanied their children with a complex chronic illness until their death, in a paediatric palliative care setting.

## Methods

Qualitative methodology, descriptive phenomenological orientation. The participants were selected intentionally, with the support of an in-hospital paediatric palliative care team. Phenomenological interviews were conducted with nine mothers. The process of analysing the data was conducted using the procedural stages of van Kaam's method modified by Moustakas.<sup>2</sup>

## Results

Understanding the essential structure of the phenomenon is revealed in a composite description that involves three essential themes: "Facing up to the harbinger of illness"; "Living (together) with a sick child" and "Starting again without ever forgetting: living with an absent child", the latter being the subject of this communication. For mothers, being reborn from the ashes and nurturing the hope of gaining the ability to rebuild themselves by refocusing on attitudes and concerns linked to promoting *self-care*<sup>3</sup> is a daily challenge.

## Conclusion

The mothers participating in this study attribute a transformative meaning to their lived experience of accompanying their children with a complex chronic illness until their death. Through this study, nurses will be able to access the lived experience of these mothers and improve their intervention throughout the process of their children's illness, as well as in their bereavement process. It will also contribute to research and teaching in palliative care in the area of child and paediatric health

## Keywords

Parents; Children; Palliative Care; Phenomenology; Nursing.

## References

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## Corresponding author:

Maria Eduarda Correia

E-mail: [eduarda.correia@ipportalegre.pt](mailto:eduarda.correia@ipportalegre.pt)

