

# The experience of family carers of children with incurable cancer: a qualitative study from the occupied Palestinian territory

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## Abstract

**Background** Treatments for childhood cancers have raised the survival rate, however different forms of malignancy continue to cause untimely deaths, and cancer remains a leading cause of death among children. Global research on paediatric cancer is limited for several reasons. Most research has focused on specific methodologies, including questionnaires with heterogeneous samples. In addition, many studies have covered a broad range of cancer diagnoses, and a wide range of children's ages and periods between diagnosis and treatment. These methods are unable to capture the essence of experiences and cultural differences. This study aimed to explore the experience of family carers of children with incurable cancer in occupied Palestinian territory.

**Methods** The study was conducted in the Paediatric Cancer Department of Beit Jala Hospital, which is the first public cancer department for children in the West Bank. The family carers of children aged 1–18 years with any type of incurable cancer in this hospital were considered eligible for participation, and the individual most involved in the care of the child was selected. To recruit participants, head nurses of medical and surgical paediatric floors provided assistance in approaching the carers of eligible children. The main objectives of the study were then discussed with the family carers. Semi-structured interviews were conducted with participants, and an interpretative phenomenological analysis approach was used to analyse the collected information. Ethical approval was obtained from the Beit Jala Hospital ethical review board and written informed consent was obtained from all participants.

**Findings** 14 interviews were conducted. Participants were nine mothers, four grandmothers, and one father. Family carers discussed their caring experiences, including their experiences in administering special treatments, their suffering due to treating irritable children, and the information given to them about their children's illness. Family carers reported that they changed the focus of their care from an initial emphasis on normalising their children's lives to relieving their physical and psychological discomfort. This change of focus accompanied changes in carers' understanding of their child's disease over time. As carers became more realistic regarding the future of their children, they attempted to make their lives as comfortable as possible. Finally, carers discussed the support system around them; they found several resources to support them in the care of their children, including the experiences of other parents of children with similar diseases, the hospital environment, and their religious beliefs. Nevertheless, they stated that they needed more support during this difficult time of their lives.

**Interpretation** There is a need to support parents of children with incurable cancer in the occupied Palestinian territory. Suggestions to improve the quality of care provided for these parents include the education and recruitment of health care professionals, including social workers and psychologists, to provide emotional and spiritual support.

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## Contributors

MA drafted the manuscript and contributed to the study proposal, data analysis, and interpretation. IR contributed to the study protocol, data analysis, and interpretation. EAS contributed to the design of the study, data collection, and interpretation of data. All authors have seen and approved the final version of the Abstract for publication.

## Declaration of interests

We declare no competing interests.

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