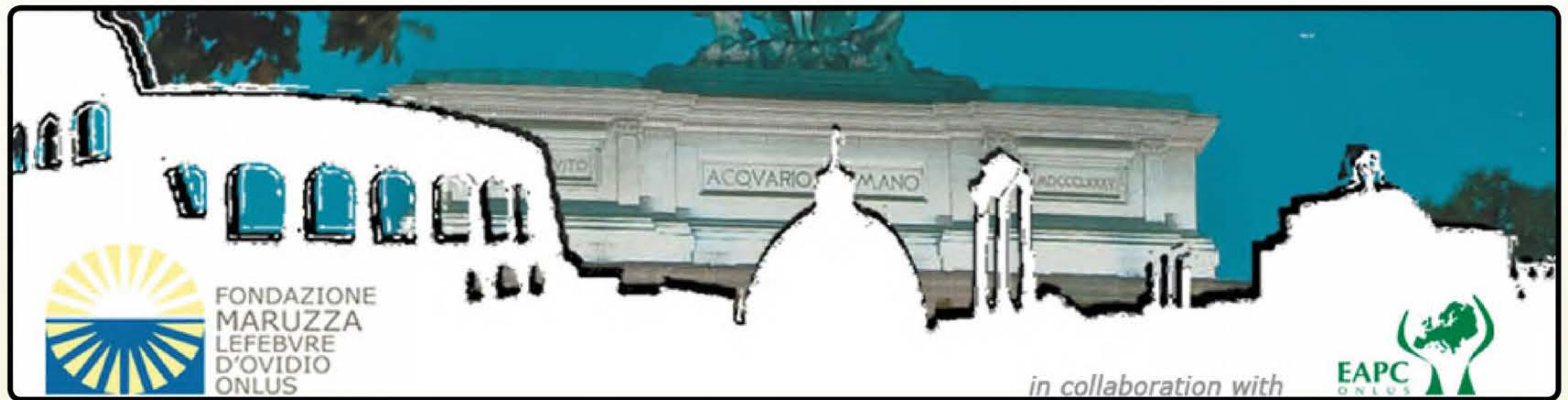


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Which needs in Paediatric Palliative Care? Identify them to orientate the Services

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Introduction

In our experience, thank to the definition of WHO and in compliance with the L.38/2010, it is important to connect the expressed and unexpressed needs of hospitalized chronic or oncological children and their families to identify an efficient clinical model of care. The Emilia Romagna Region, through dedicated workgroups and specific Commissions, is involved in the project for Paediatric Palliative Care Network (Hospitals, Hospice and Territory); the Italian Society of Psychosocial Oncology (SIPO), Emilia Romagna Section, intends to contribute to the development of dedicated Services, through a research focused on the children and their families point of view.

Objectives and Methods

SIPO proposes an action research to explore "the needs of patients and their families", in different moments of illness history. At first, 3 Paediatric Hospitals (Parma, Bologna, Rimini), specialized in the care and clinical assistance of chronic and oncohaematological diseases, will be involved. In a second step the research will be extended to other units.

In the three centres, with the contribution of SIPO psychologist facilitators, will be identified 15 clinical situations, distributed in the following conditions:

- A. 5 cases, at the moment of diagnosis (enrolled in progressive order from the initial date of care),
- B. 5 cases, of chronic illness,
- C. 5 cases, of progression or relapse

Tool

Two types of tools, related to the chronological and developing age of the patient, specially created for this research, are suggested:

- Semi-structured interview for the patients (children and adolescents), administered by the psychologists of the centres, during a clinical interview;
- Semi-structured interview for the care-givers of little children (under six years old).

Aim

The aim of the study is to give back to Emilia Romagna Region (Work Table of Paediatric Palliative Care) an exhaustive cross section of the main needs of patients and families, during the long and difficult experience of disease, able to orientate the clinical assistance from the Regional Paediatric Palliative Care Projects.