INTERFASOL Final Conference
ISCH COST Action IS1311
Experiences with INTERFASOL
(Training Schools)

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Resilience
as the possibility of personal and relational transformation as well as the growth that subsists beyond adversity
Palliative care for children: what are we talking about?

Conditions for which curative treatment is possible but may fail
(Ex.: advanced or progressive cancer or cancer with a poor prognosis; complex and severe congenital or acquired heart disease)

Progressive conditions in which treatment is exclusively palliative after diagnosis
(Ex.: progressive metabolic disorders; certain chromosomal abnormalities such as trisomy 13 or trisomy 18)

Conditions involving severe, nonprogressive disability, causing extreme vulnerability to health complications
(Ex.: severe cerebral palsy with recurrent infection or difficult-to-control symptoms; extreme prematurity; severe neurologic sequelae of infectious disease; hypoxic or anoxic brain injury and other severe brain malformations)

Conditions requiring intensive long-term treatment aimed at maintaining the quality of life
(Ex.: HIV; cystic fibrosis; severe gastrointestinal disorders or malformations; severe epidermolysis bullosa; severe immunodeficiencies; renal failure in cases in which dialysis, transplantation, or both are not available or indicated; chronic or severe respiratory failure; muscular dystrophy)

(Himelstein, Hilden, Boldt, & Weissman, 2004)
Palliative care for children: what are we talking about?

• Palliative care for children (WHO, 1998a):
  
  • It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease
  • Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
  • Requires a broad multidisciplinary approach that includes the child/family and community resources
Palliative care for children: what are we talking about?

• About 6,000 children (0-17 years old) living with palliative needs in Portugal (data from 2013)
  • The vast majority without access to this kind of care

• About 200 deaths per year due to chronic complex pediatric disease (1-17 years old)

• A single inpatient unit specialized in pediatric palliative care in the country

Development of family resilience in the context of pediatric palliative care: why?

• An uninvited family guest...

• Illnesses that threaten and/or limit the child's life have a profound individual and systemic impact (Steele & Davis, 2006)

• A considerable majority of children/families, even after facing severe or chronic adversity, demonstrate some resilience processes (Masten, 2014).
Family resilience

• It involves more than coping only with the challenging situations themselves: it involves the possibility of personal and relational transformation as well as the growth that subsists beyond adversity.

• Families can emerge from the most challenging situations more empowered to deal with future challenges.

• There are families that come out stronger from the experience of crisis than others.
  • What factors can explain?
  • Strengthening the family: our research focuses on family resilience.
Family resilience: risk factors

- **Family-related variables:** pre-existing family conflicts
- **Individual variables:** stress; psychological symptoms; age; schooling; the specificity of the disease
- **Context-related variables:** absence of support; loneliness

(Giallo & Gavidia-Payne, 2006; Rosenberg et al., 2013).
Family resilience: protective factors

• As family-related variables, family cohesion, effective family communication, and the maintenance of trusting and positive relationships among family members contribute significantly to a greater capacity to deal with challenging situations.

• Individual variables: optimism, ability to seek help.

• Context-related variables: availability of the support team; community resources; support networks.

• It seems important to understand whether the resilience of the sick child will be in any way related and / or dependent on the resilience of the remaining subsystems of the family.

(Giallo & Gavidia-Payne, 2006; Rosenberg et al., 2013).
Family resilience: family-related variables

• Intergenerational family solidarity may contribute to the strengthening of protective factors:
  • Throughout life, receiving and offering emotional support is an important dimension in the relations between parents and children.
  • When facing illness, family members are often the primary providers of support, both within the same generation, but also, and increasingly, between generations.

So, what do we want to know more about?

• Identify and analyse the relationship between risk and protective factors and their contribution to the positive adaptation of the family to the illness experience

• Evaluate the mechanisms and psychological processes implemented by family elements that are precursors of family resilience

• Test the impact and efficiency of interventions on indicators of family resilience and their variations according to family characteristics and intervention

• Answer the gaps found in terms of psychological intervention in pediatric palliative contexts, expecting to develop an intervention model with an emphasis on family resilience that may contribute to the increase of public policies related to the promotion of welfare.
The research plan

Includes 4 distinct studies:

• The first study, with an exploratory nature
  • Interviews with families and directors of institutions providing care for children with complex chronic illness

• The second and third with a confirmatory nature
  • Family interview with narrative analysis: each member will be asked to record an experience they consider personally and emotionally important for 15 minutes on 3 consecutive days.
  • In a domiciliary context, development of a family intervention model that promotes its resilience (6-8 weeks).

• The fourth with the purpose of evaluating the quality of interventions from the participants’ point of view.
First observations resulting from the development of the research

• 166 institutions contacted
  • 33 institutions that agreed to collaborate (schools, clinics, non-governmental associations)
  • More than 100 participants (at the moment, mothers and fathers)
  • Interviews with directors of institutions providing care for children with complex chronic illness
First observations resulting from the development of the research

• Difficulties in accessing families/ non-acceptance of participation by the institutions
  • Families burden with participation in research projects
  • Institutions considered they didn’t have families facing life threatening/limiting illnesses (we only requested collaboration to institutions with complex chronic disease situations reported!)

• Problems with:
  • Lack of awareness of the concept of pediatric palliative care by institutions and families:
    • Refusal to participate in the study/difficulty in accessing the sample and meeting the schedule
  • The word "disease", which is present in most of the instruments used, is not always consensual:
    • Replacement by "health condition" or "child's difficulties / needs"
First observations resulting from the development of the research

• Strong need of:
  • families and carers to be supported and cared for by a more responsible and caring State
  • a better balance and coordination between informal and formal care
  • the development of appropriate public policies
What about the training schools: how they helped me?

• COST Training School at Keele University (11\textsuperscript{th} to 15\textsuperscript{th} May, 2015).

• COST Training School at the Faculty of Psychology and Educational Sciences - Porto University, Portugal (4\textsuperscript{th} to 8\textsuperscript{th} April, 2016).
What about the training schools: how they helped me?

- My expectations were to learn more about European projects, policies and research about intergenerational family solidarity and support systems centered on family, mainly on health and community contexts. **Develop interdisciplinary research capacity**, the training school’s global objective, was especially relevant to my PhD research theme, but also to improve my professional expertise, since I work in a community team, where the intergenerational family solidarity domain is central for social support networks.

- The main contributions achieved for my own research project, besides the inputs on statistics and research methods given, were related to the **meaning and reach of the concepts of support and providing care**. Indeed, we are assisting to changing concepts and determinants applied to the ground of health and family, especially when facing the children provision of care to their parents in a near future, looking important to invest in the child’s education.

- As a special added value of these events I found the opportunity to be in contact with different research interests, which was an exceptional chance for exchange of experience and to **familiarize with best practices** as a path for my personal and academic development.