

## CONFERENCE ABSTRACT

### PRINCEP program: clinical program for specialized and integrated care of paediatric patients with complex chronic conditions.

16<sup>th</sup> International Conference on Integrated Care, Barcelona 23-25 May 2016

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**Introduction:** With the development of the science and technology applied to health, infant mortality has drastically dropped in the last half century. This longer survival has led to a new phenomenon: the increase in pediatric complex chronic conditions (CCC). Recent studies have described the increasing prevalence of CCC among all pediatric hospitalizations in the United States, accounting for 10% of all pediatric hospital admissions and 40% of pediatric hospital charges (Simon et al. Pediatrics 2010).

CCC are associated to lifelong disabilities, medical fragility, functional limitations that require assistance from technology, and a high dependency from the health care system. A child with CCC has a great impact in the family, who experience deep organizational and emotional changes. In many cases other social factors like poverty, job insecurity, level of education and place of residency play also a role in this health process.

In response to this situation, our institution developed a multidisciplinary team (called PRINCEP program) in 2012 addressed to these patients. PRINCEP program is aimed to offer integrated care for patients who are dependent of technological assistance, need specific case management or regular use of hospital facilities.

**Description:** PRINCEP is structured in a multidisciplinary team that includes pediatrician, nurse, social worker and psycho-spiritual specialist, with the following objectives:

- To offer a family-centered and integrated social and health care to pediatric patients with CCC.
- To improve the care experience of these patients and families, stimulating their self-care.
- To optimize resources use reducing costs.
- To promote the continuity of care during the transition to adult care, ensuring that patients reach adulthood in the best conditions.

Target population is selected using the following criteria (main plus 2 or more complementary criteria are needed):

- Main criteria: incurable disease with life expectancy greater than 12 months.

Ricart; PRINCEP program: clinical program for specialized and integrated care of paediatric patients with complex chronic conditions.

- Complementary criteria: 2 or more severe chronic conditions associated with medical fragility, regular consultation with 3 or more subspecialists, need of technological assistance (gastrostomy or tracheostomy tube, mechanic ventilation...), more than 2 unplanned admissions per year, substantial social vulnerability.

PRINCEP provides coordinated care between inpatient (specialist) and outpatient services (primary care, schools, early childhood development centers, social services). Patients can contact the team by mobile and webmail the 24 hours a day, 365 days a year.

**Key findings:** From October 2012, when PRINCEP was established, there has been a progressive increase in the cases managed: 22 in 2012, 68 in 2013, 97 in 2014 and 111 in 2015. There are 4 main groups of patients: polymalformative or genetic syndromes (frequently affected by rare diseases), severe neurologic diseases, epidermolysis bullosa, and technology-dependent children.

From 2012 to 2014 a decrease was seen in: the average yearly admissions per patient (from 5.7 admissions/patient/year in 2012 to 0.94 in 2014,  $p < 0.001$ ); the hospital stays (from 73 days/patient/year to 9.5,  $p < 0.0001$ ), the average length of hospital stay (from 12.9 days/admission to 8.8,  $p < 0.001$ ), the yearly outpatient visits (from 68.9 visits/patient to 21.3,  $p < 0.0001$ ) and the yearly emergency room visits (from 8.5 visits/patient/year to 2.0,  $p < 0.0001$ ).

The 43% of families had indicators of high risk of social vulnerability, so they underwent intensive follow up by the social worker.

**Highlights:** The care of children with CCC requires transversal skills that could respond to these patient's needs: not only the medical and technology ones, but also the derived needs of the new social and family situation.

The main qualitative results of PRINCEP program are: greater satisfaction of the patient's families because of having a leader coordinating team; improved use of community services by these patients, with better integration to its community and less disruption in their daily life; increased satisfaction of health professionals; and optimization of health resources because of the drop in admissions and outpatients visits.

**Conclusion:** PRINCEP program is efficient in the care of CCC children with social vulnerability. Its implementation to other areas would allow better care coordination and savings in health and social costs. It is also expected to obtain long-term benefits for the health system: a greater number of CCC children will reach the adulthood in better conditions, being well integrated in its community and well known for the professionals, allowing the optimization of resources and the patient's well-being.

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**Keywords:** pediatric complex chronic conditions; family-centered care; integrated care; care continuum; patient experience

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