



HOME CARE AND PALLIATIVE CARE IN RARE DISEASES

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SUMMARY

The World Health Organization (WHO), defines Pediatric Palliative Care as *comprehensive care for patients whose disease does not respond to curative treatment. The control of pain and other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is to achieve the best quality of life for the patient and their families.*



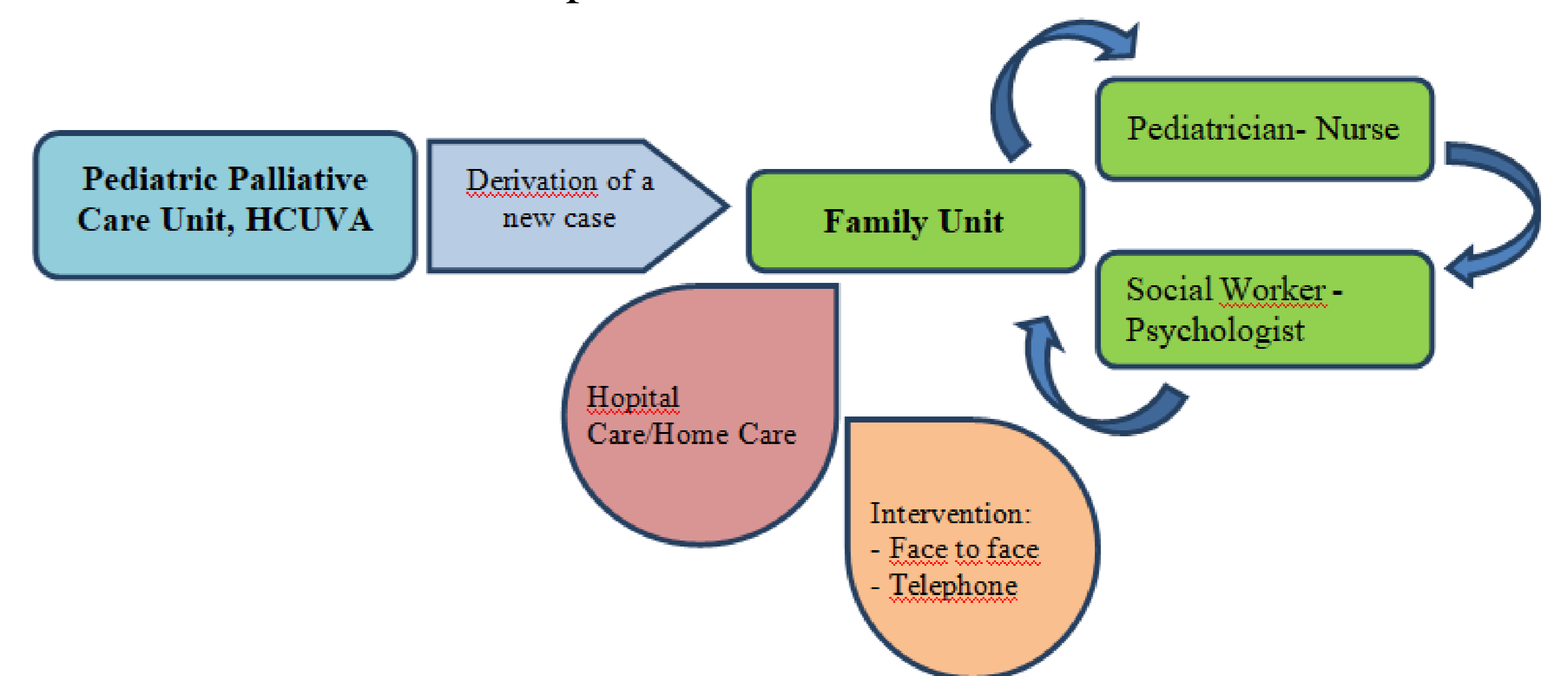
The Association for Rare Diseases **D'Genes** it is composed of parents, families, professionals in all fields in order to create opportunities for exchange and fellowship among friends and people diagnosed with Rare Diseases (RD), and awareness of the public health problem posed by low-prevalence diseases. It belongs to FEDER, EURORDIS and ALIBER, and among its objectives are take action to improve the quality and life expectancy of patients and their families and preventing isolation. Following our objectives, since January 2016, our Entity participates in the **Pediatric Palliative Care Program** together with the Virgen de la Arrixaca Clinical University Hospital (HCUVA, Murcia) and AFACMUR (Association of Family Members of Children with Cancer of Murcia). The **main purpose** to this project is improve and increase the attention and quality of life of pediatric patients and their families in the situation of terminal illness or without response to treatment, in a comprehensive and individualized manner, guaranteeing respect for their dignity and right to their autonomy.

D'GENES IN PEDIATRIC PALLIATIVE CARE – OUR PROJECT

In Spain, around 3,000 children die every year. Although childhood mortality has declined, the prevalence of incurable diseases and disability has increased. More and more children are surviving in situations of high vulnerability and fragility, sometimes for years. Around 50% of deceased children die from serious life-limiting diseases (40% due to oncological pathologies and 60% to other diseases). In the Region of Murcia it is estimated that the number of children under 18 years is 335,000 thousand, of which approximately 543 suffer from life-limiting diseases and between 204 and 272 require specific Pediatric Palliative Care. It is expected that between 65 and 89 children will die each year.

At present, the multidisciplinary team of the Unit is composed of:

- ✓ Health Personnel (hired by the Murcia Health Public Service):
 - 3 Pediatricians (one of them coordinator of the program); 3 Nurses. They work in pairs.
- ✓ Psychosocial Care Personnel (private entities)
 - 1 Social Worker and 1 Psychologist of D'Genes, who managed RD cases and other pathologies.
 - 1 Social Worker and 1 Psychologist of AFACMUR, who managed oncological diseases cases.
 - 1 Counselling (support and accompaniment of the grieving)

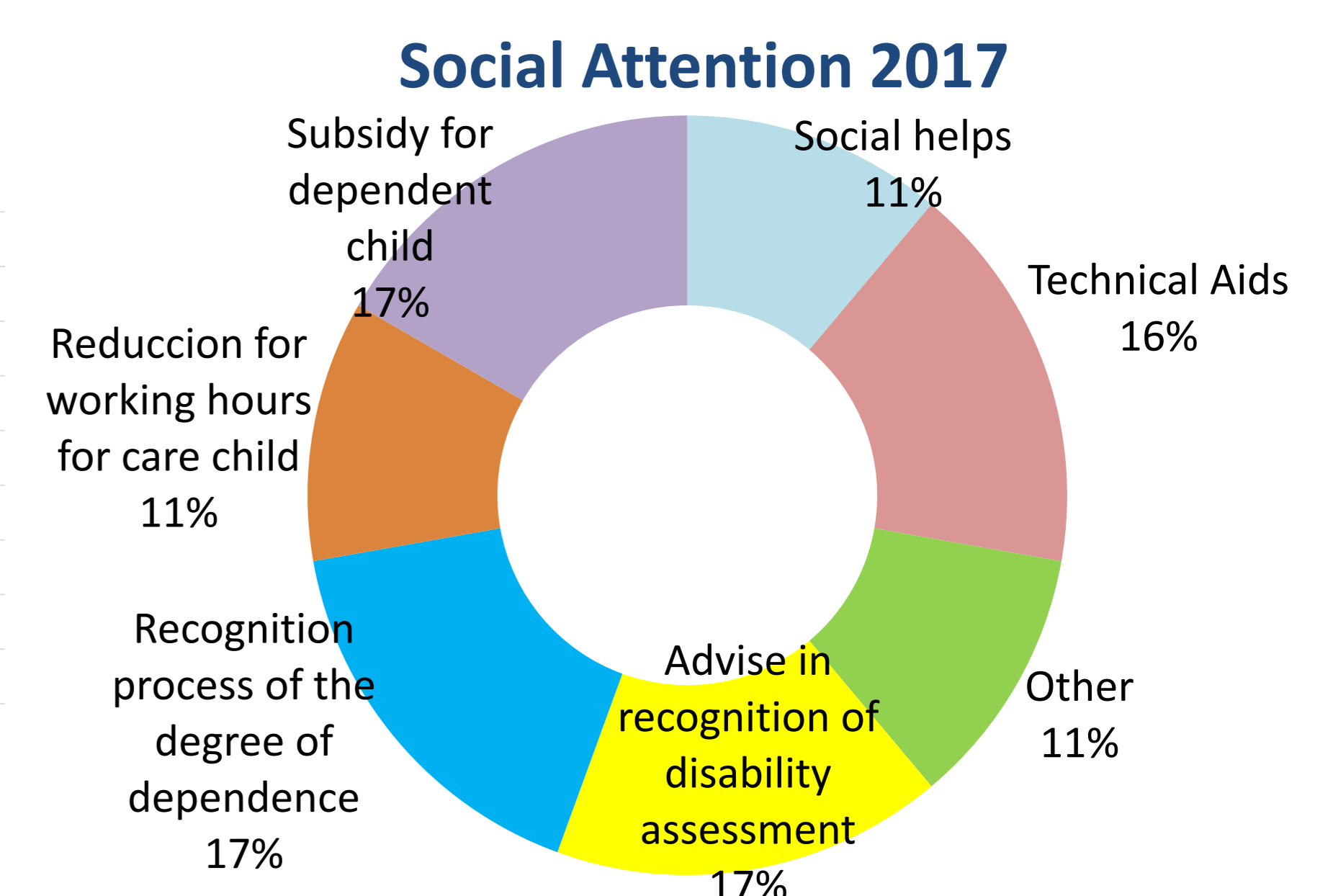
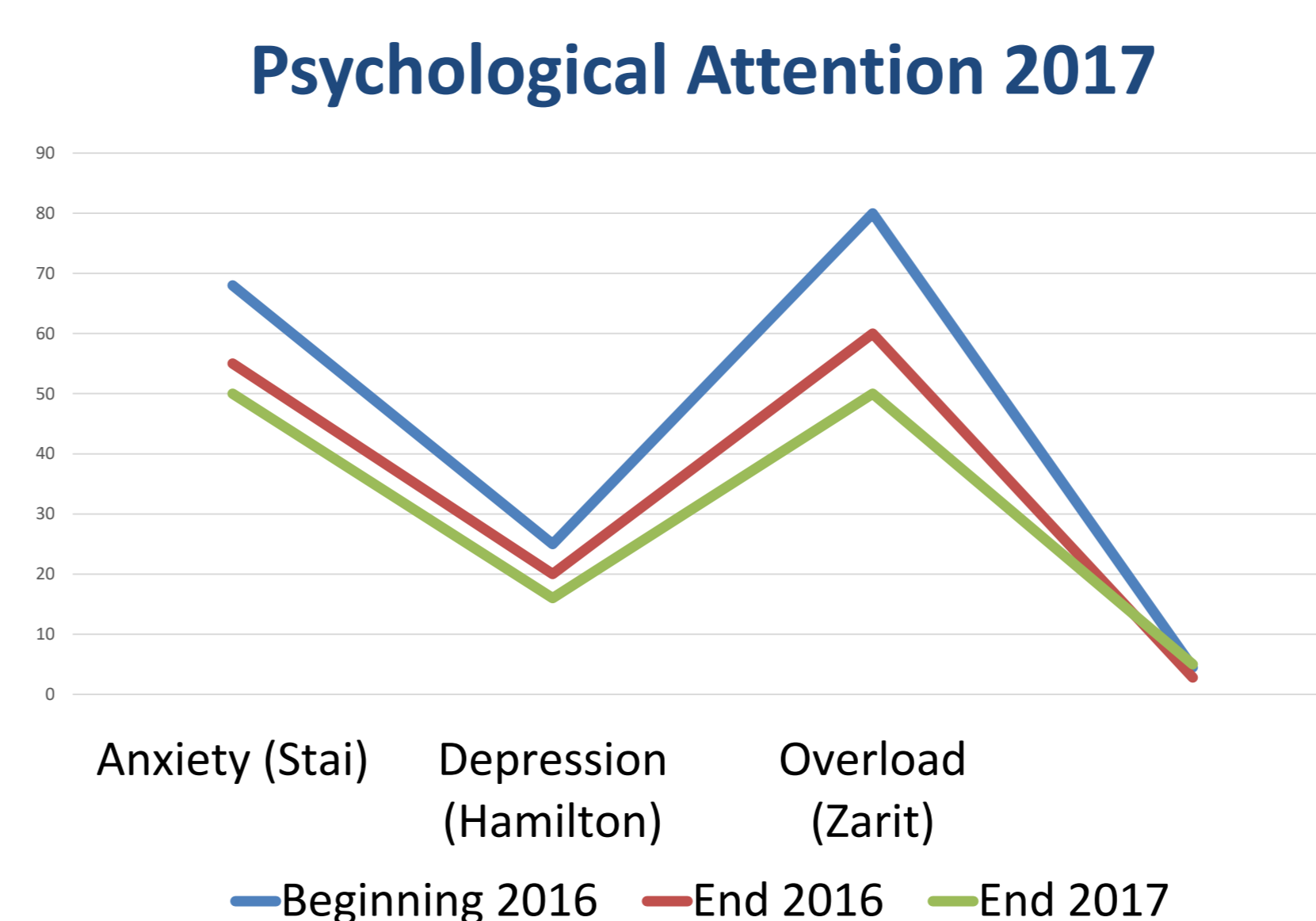
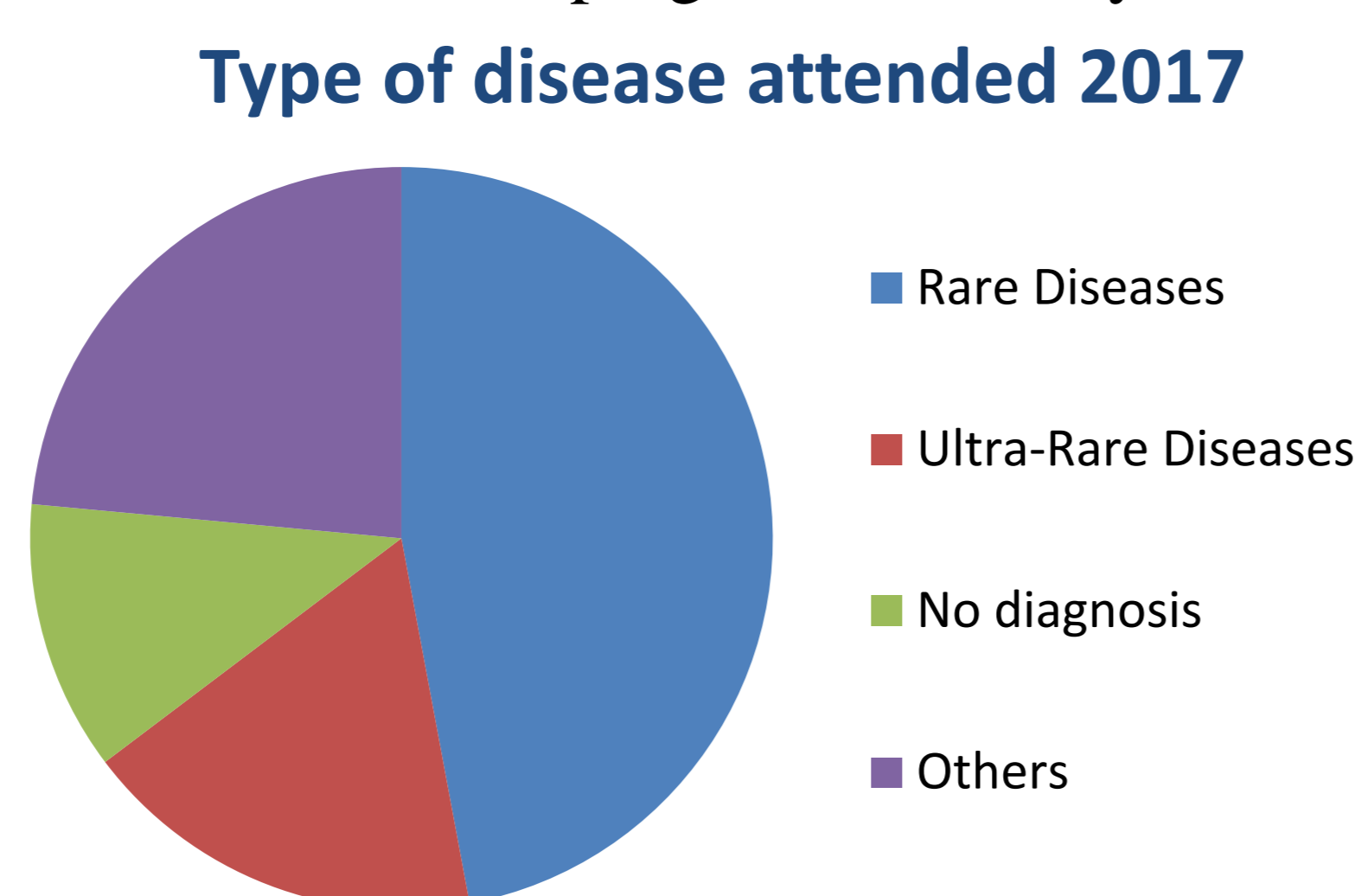
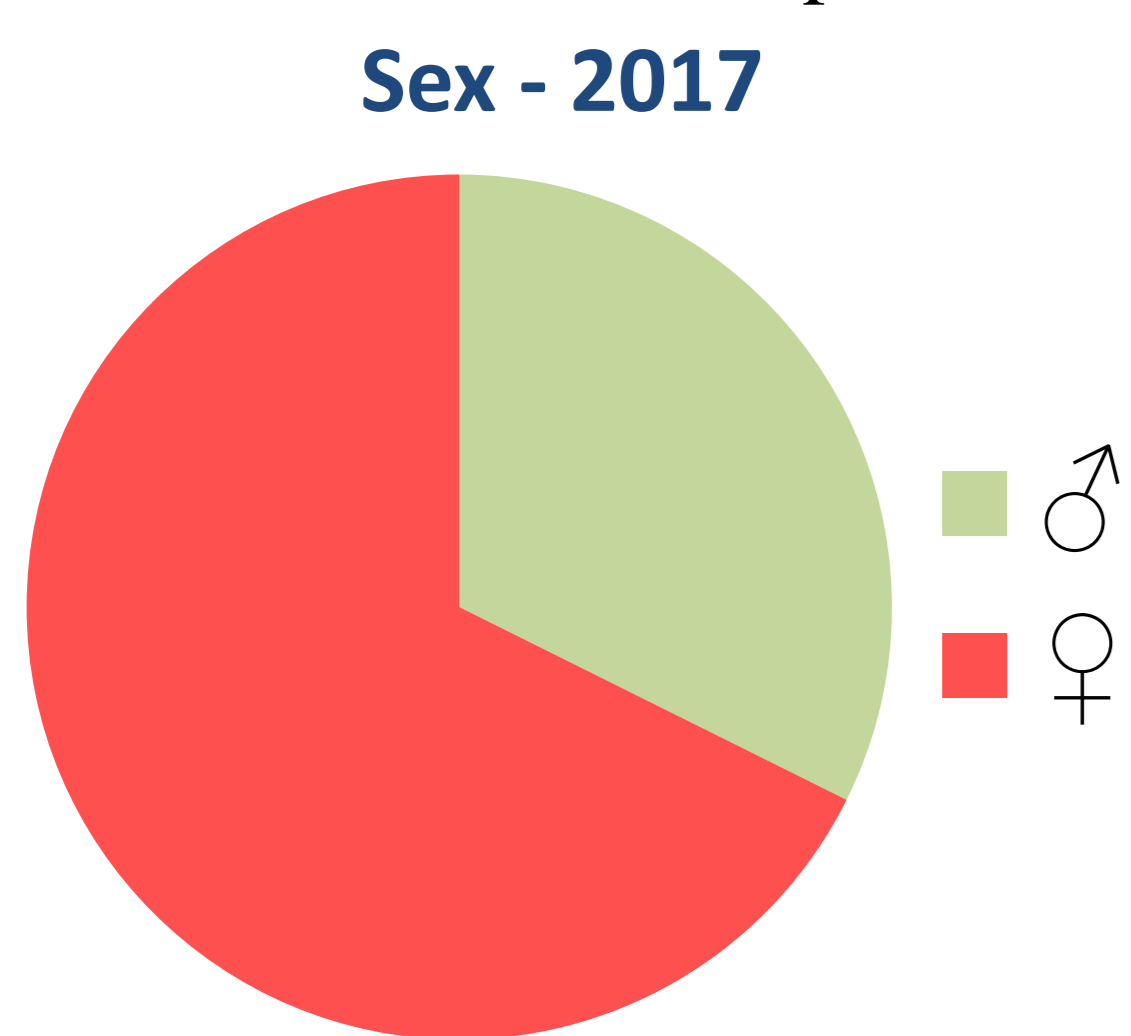


F1. Case management scheme. Procedure and resources

All the support is free, with any cost to families, Family support continues after the child's death, continuing to support the grief as long as necessary or when the family considers it necessary. The attention is carried out in person in the House, Hospital or center (35%) and telephone form (65%).

D'Genes attended in 2016 34 cases (10 deaths, 1 discharge of service), in 2017 34 cases (11 new cases, 5 deaths) and actually attends 35 cases. The work objectives are:

- ✓ Offer a multidisciplinary and integral assistance to respond to the needs of patients and their families.
- ✓ Manage social resources to meet the needs that appear in the process of the disease.
- ✓ Give psychological and emotional support necessary to face the death, avoid a pathological grief and offer the necessary emotional support to follow up on grief once the patient has died.
- ✓ Manage funeral and burial aids for families that do not have economic resources.
- ✓ Create an specific resources, educational programs and carry out research in Pediatric Palliative Care



CONCLUSIONS

The benefits that provides Pediatric Palliative Home Care are:

- ✓ For **patients**: better QOL, better control of symptoms, income and hospital visits are avoided and child remains in his family environment, reducing the feeling of fear, isolation and helplessness.
- ✓ For the **family**: reduction of the social cost (less time off work for family members, less psychological problems), greater emotional support from family and friends. Home care does not hinder family dynamics and family members can share responsibilities in the care of the child. Encourages the participation of the patient's siblings in care making it easier to address their feelings.
- ✓ For **society**: decreases in income and visits and the consumption of health resources (hospital admissions, emergency consultations, etc.).

It is necessary to improve the times of management of social aid, since 100% of minors die without having resolved the condition of disability. Likewise, care at home allows a better family dynamics and reduce levels of anxiety and discomfort, as well as times of incorporation into working life.

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