5TH MARUZZA INTERNATIONAL CONGRESS ON PAEDIATRIC PALLIATIVE CARE

HOSPICE PEDIATRICO-AZIENDA OSPEDALE
UNIVERSITA' DI PADOVA
DIPARTIMENTO DI SALUTE DELLA DONNA E
DEL BAMBINO,
CENTRO REGIONALE VENETO DI TERAPIA
ANTALGICA E CURE PALLIATIVE PEDIATRICHE

Advanced care planning to protect the wishes of the child and family

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Background

Advance care planning (ACP) represents an essential moment of Pediatric Palliative Care (PPC), implemented through a communication and decision-making process involving team, child and family. In Italy the ACP is included in a Law (219/2017) to guarantee the citizen who is free to decide according to the principle of self-determination, the implementation or not, of health treatment.

The distribution of PPC services in Italy is still dispersive even though there is a Law (L38/2010), which guarantees the citizen's right to access PPC and Pain Treatment services

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In Veneto (Nord-East Italian Region of 8 millions of inhabitants), since **20 years there is the Pediatric Pain Therapy and Palliative Care Center**, which take care of around 250 children/year both offering indoor and outdoor services.

Padua

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The purpose of our study was to verify the adherence to the advance care planning choice (ACP form) and to the preference of the death place.

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Methods

In this observational study, conducted in 2022, we analyzed the ACP form of all children followed by our PPC center who died during the last three years. The inclusion criteria was to have a defined ACP.

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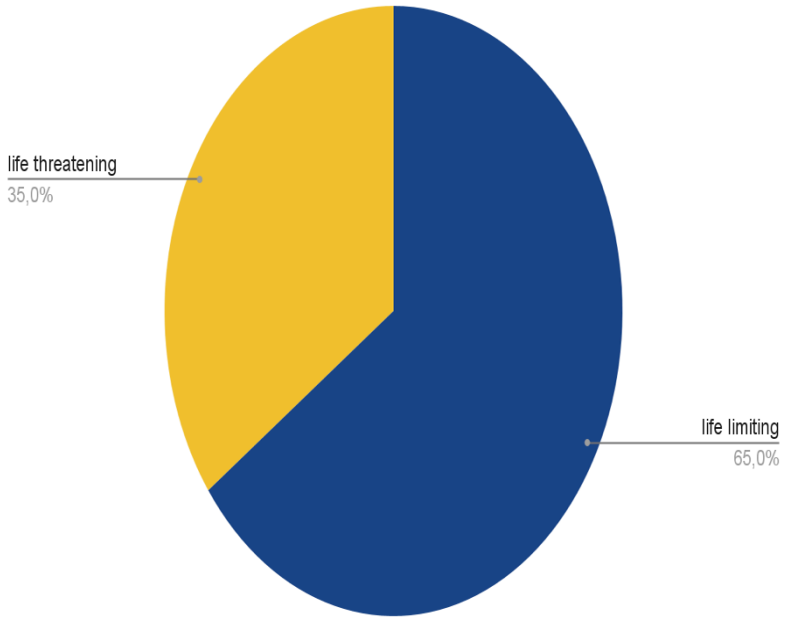
Results

98 childrens died in the period (2019-2021)

65% (64 children) with a l**ife limiting disease**, and

35% (34 children) with **oncological incurable disease**.



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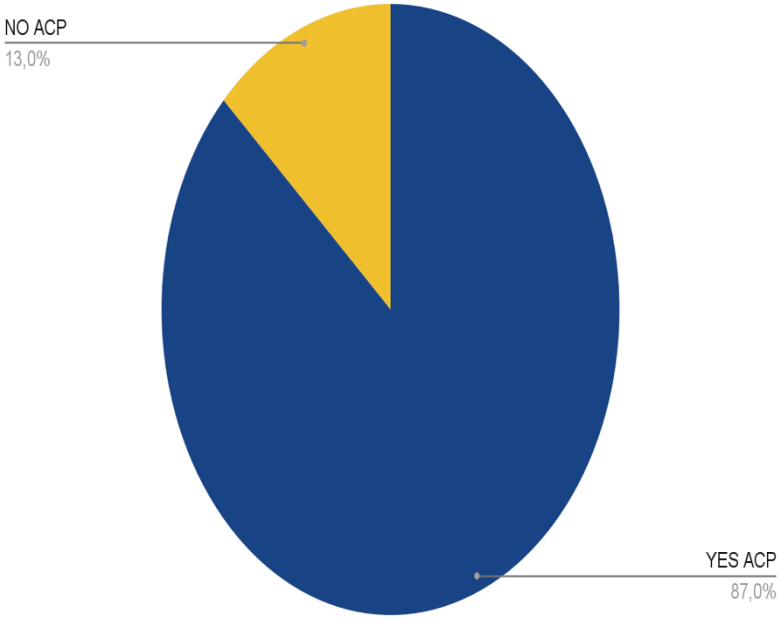
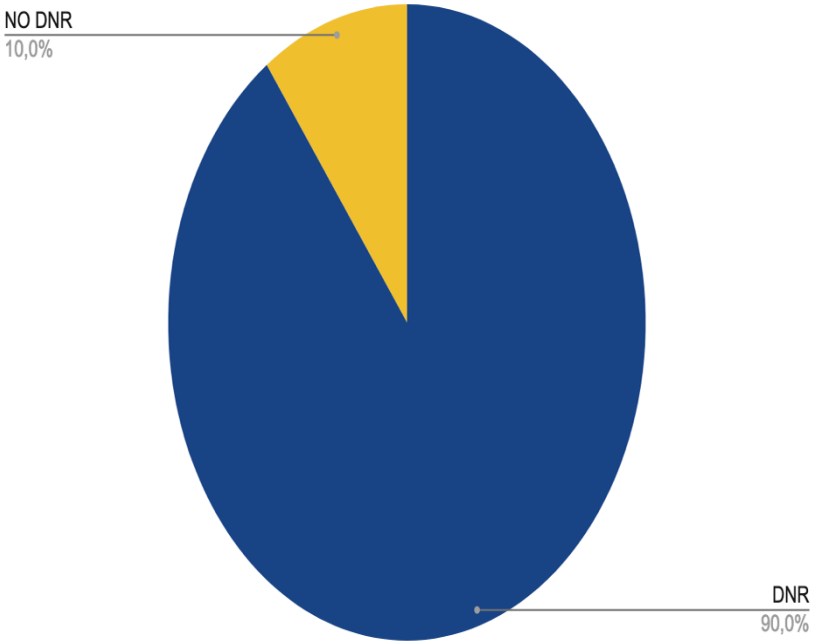
Results

87% children (N 85) had a defined ACP

90% among these had a shared **Do Not Resuscitate** (DNR) order.





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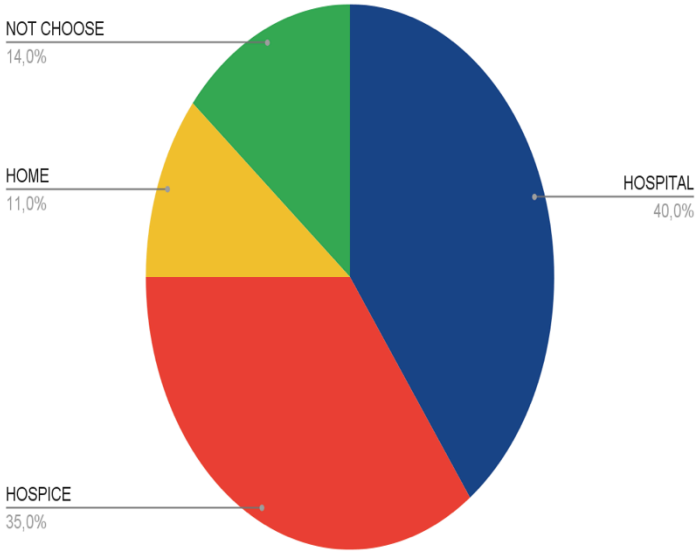
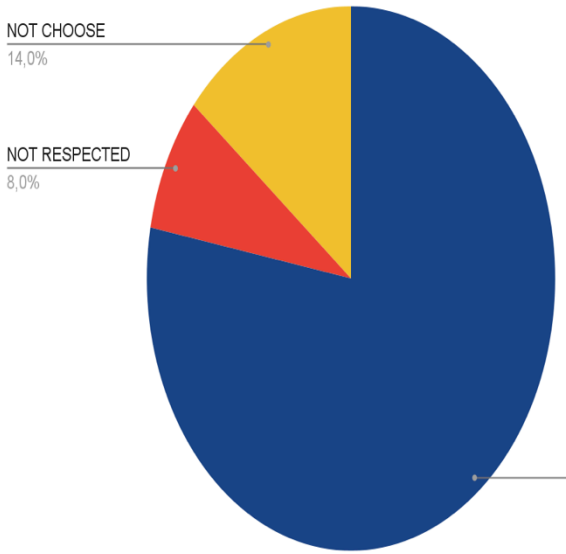
Results

66 children (78%) died in the chosen place and the ACP was so respected.

34 children (**40%**) die at the local Pediatric **Hospital**, 30 children (**35%**) at Pediatric **Hospice**;

9 families (**11%**) prefered **Home**, 12 families (14%) hadn't choose a favorite place of death.





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Discussion

The ACP of children on the PPC Center care was **respected for almost all the children**.

Some sudden deaths were those situations in where the preferred place was not respected (total n.14).

At the end of life, families mostly prefer to be at the local pediatric hospital or at the pediatric hospice, to achieve a better end of life symptoms management.

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Conclusion

In conclusion, the best end-of-life-management place is that where the child and the families **feel more safety and homely, not necessarily the child home**. No less, improving the care at home with a pediatric palliative care network, offering 24/24 care everywhere, could offer more choices to the child and family, ensuring quality of life and quality of care in the end of life too.

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Thank you for your attention!