

“The characteristics of children in need of Palliative Care with perspective from parents and health care workers”



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Paediatric Palliative Care Overview

- Paediatric palliative care is a subspecialty that focuses more on improving quality of life for children with life threatening conditions
- According to the WHO, Paediatric palliative care involves the child's body, mind and spirit, but it also involves giving support to the family

- WHO in 2018, reported up to as high as 21 million children needing palliative care with about 2.5million children dying of serious health related suffering
- About 98% of these children are in the low-& middle-income countries (LMIC)

PNG

- Data in PNG?
- Similar to other LMIC, there is a lack of specialised Paediatric palliative care services
- Children with palliative care needs are being cared for in general paediatric wards by paediatric doctors and nurses

Aim

- Describe the characteristics of children with palliative care needs and the quality of Paediatric Palliative Care provided

Method

Study design & site: Descriptive qualitative study carried out from March to July, 2022 in PMGH Paediatric Wards

Data Collection:

- I. Patient's chart for demographic information and clinical details
- II. Semi-structured questionnaire for in-depth interviews on parents
- III. Focus group interviews for health care workers

Categories of life-threatening illness

Category 1	Category 2	Category 3	Category 4
<p>Children with life-threatening conditions for which curative treatment may be feasible but can fail</p> <p>E.g.: Cancers Complex CHDs RHD</p>	<p>Children with conditions in which there may be long phases of intensive treatment aimed at prolonging life, but premature death is still possible</p> <p>E.g: HIV, COAD</p>	<p>Those children with progressive conditions without curative treatment</p> <p>E.g.: Neurodegenerative conditions, metabolic conditions and neuromuscular conditions</p>	<p>Those children with conditions with severe neurological disability, which may deteriorate unpredictably, but are not considered progressive</p> <p>E.g: Cerebral palsy, hypoxic brain injury</p>

Method

Data analysis:

Thematic analysis i.e. paper based approach , for parent and staff interviews

- Parents and health care workers gave consent
- Ethical Approval: Ethics committee of the SMHS, UPNG

Result

1. Patient's characteristics
2. Thematic analysis of Parent/Guardian Interviews
3. Thematic analysis of Staff Interviews

Patient's characteristics

1. Demographics

Median age range:

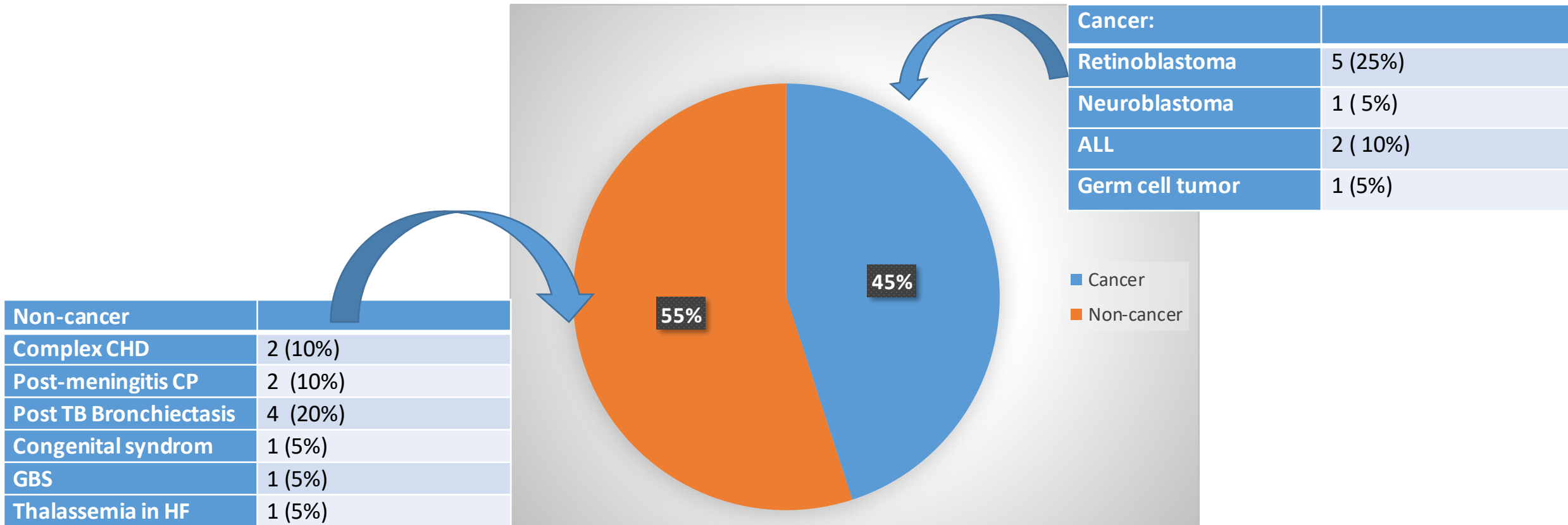
Mean +/- SD:

To figure out and use instead
of the age range

Parameters	n = 20 (%)
1. Sex	
Male	11 (55%)
Female	9 (45%)
2. Age range	
<1yo	3 (15%)
1-5yo	6 (30%)
5-10yo	4 (20%)
10-15	6 (30%)
15-20	1 (5%)
3. Region	
POM	13 (65%)
Provincial Referrals: Madang, East Sepik, Hela, New Ireland, AROB	7 (35%)

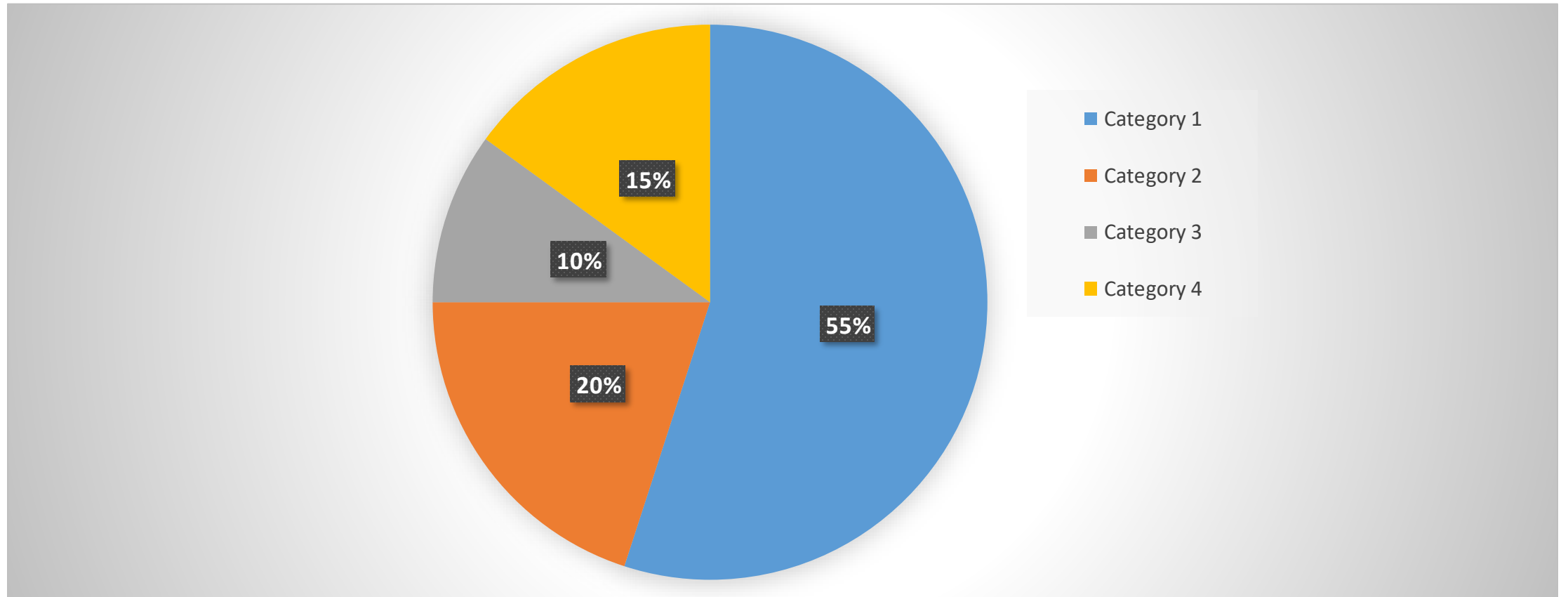
Patient's characteristics

2. Classification of diagnosis



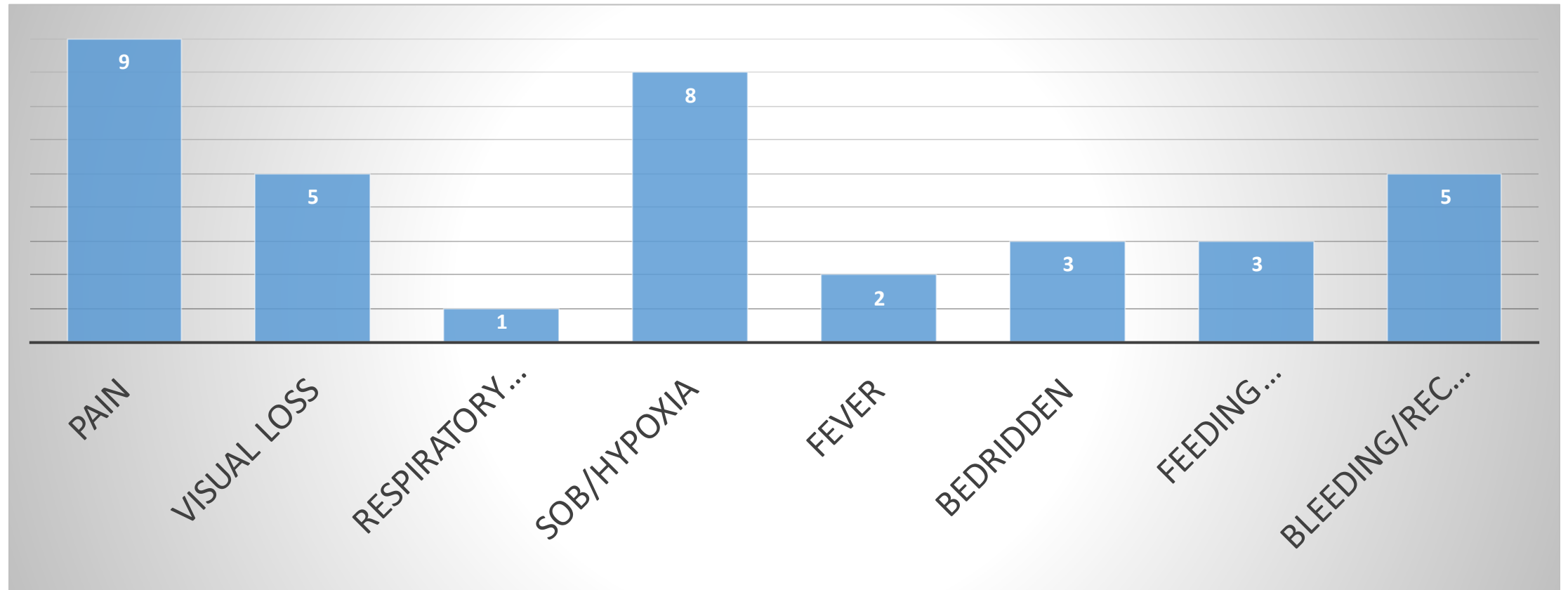
Patient's characteristics

3. Category of Life threatening illness



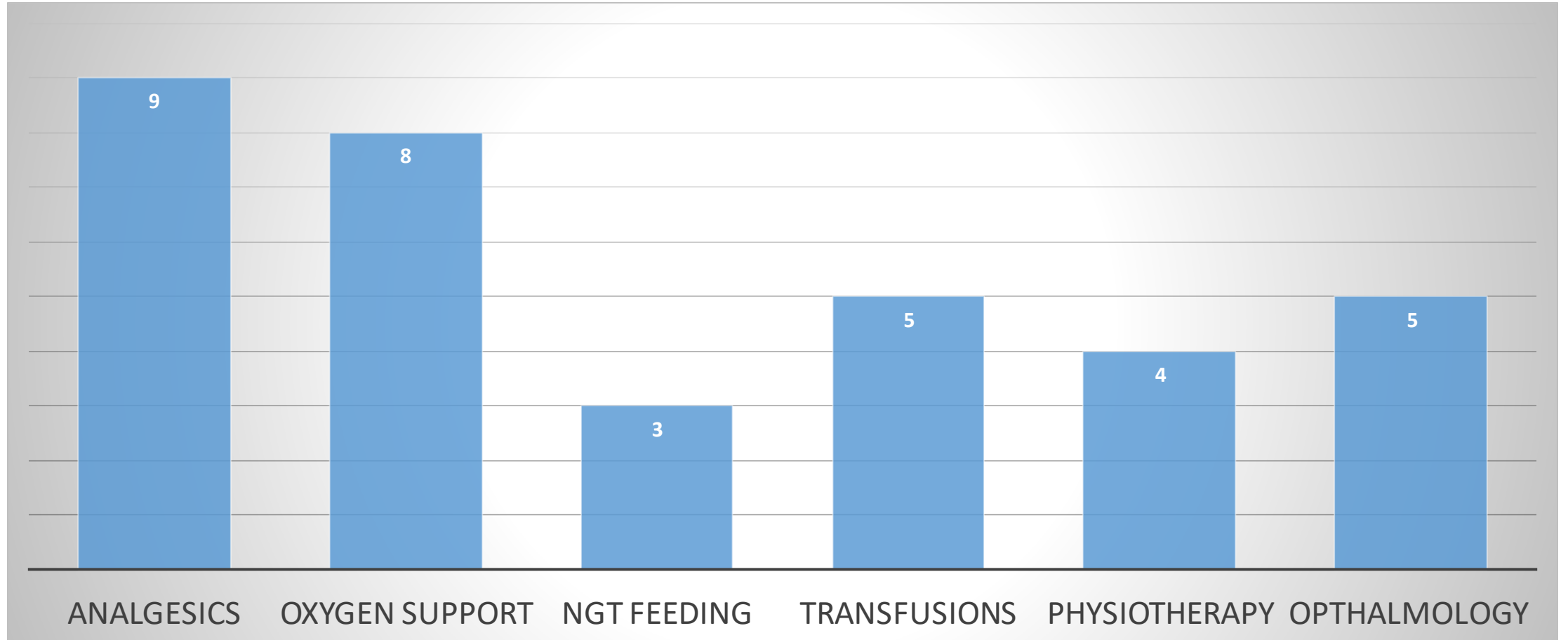
Patient's characteristics

4. Frequency of symptoms



Patient's characteristics

5. Frequency of Interventions



Thematic analysis of Parent/guardian interviews

Parent/guardian's Perspective

1. Child's diagnosis

- Understanding of diagnosis
- Identification of Palliative care needs
- Emotions toward diagnosis <..\HYPERLINK\PARENTS%20GUARDIANS%20PERSPECTIVE%20ON%20DIAGNOSIS.pptx>

2. Child's Management

- Parents involvement
- Satisfaction <..\HYPERLINK\PARENTS PERSP ON CHILDS MX.pptx>

3. Child's Outcome

- Discussed with parents?
- Emotion toward child's possible outcome <..\HYPERLINK\PARENTS PERSP ON CHILDS OUTCOME.pptx>

Thematic analysis of health care workers interviews

HEALTH CARE
WORKERS
PERSPECTIVE ON PPC,
(n=10 NO)

1. Understanding of
Palliative care



- Own definition of PC
- First instinct
[..\HYPERLINK\Staff
definition PPC.pptx](..\HYPERLINK\Staff definition PPC.pptx)

2. Ability to assess a child
with PC needs



- Ability to assess:
- Severity of pain
 - Spiritual needs
 - Psychosocial [needs](#)

3. Addressing PC
needs of a child



- Ability to address:
- Pain
 - Spiritual needs
 - Psychosocial needs
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ability to address PC
NEEDS.pptx](..\HYPERLINK\Staff ability to address PC NEEDS.pptx)

Discussion

- Polysymptoms highlights the importance of systemic assessment, identification of problematic symptoms and prioritizing management
- Pain (45%), the most common symptom of patients with life threatening illness
- *C.Feudtner, et al (2021). Polysymptomatology in Pediatric Patients Receiving Palliative Care Based on Parent Reported Data*

Discussion

- *E. Gorkora etc (2014). Parent's experience with a dying child with cancer in palliative care*
- Diagnosing a child with life threatening illness causes existential shock to parents & affects the family's daily lives
- Main vision of palliative care which involves
 - > symptom management
 - > spiritual, emotional & psychological support for child & family
 - > Support to families after the loss of their child

Recommendation

- In our setting, Paediatric palliative care is integrated into the standard care, which is beneficial but to an extent
- There is a need for Paediatric palliative care team
- The findings of this study will help improve Paediatric palliative care
 - Create a policy on Paediatric palliative care
 - Improve quality of care
 - Further research

Study limitation

- I was the moderator in the staff focus group interview –Bias
- No data on social worker, psychiatric and pastoral care intervention

Acknowledgement

- 20 children and their parents and guardians
- 1E & 1BA Nurses
- Supervisors: Prof Duke, Dr Anga, Dr Pulsan
- Colleague Registrars

Reference

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