



Improving the Palliative Care Access for People with Intellectual Disabilities

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Disclosures

I have no actual or potential conflict of interest in relation to this program/presentation.

Introduction

People with intellectual disabilities (IDs)

- Prevalence: 1-1.2% (total number: 77000-90000 in Hong Kong) ¹
- Definition: condition characterized by significant limitations in both intellectual functioning and adaptive behavior that originates before adulthood ²
- Life expectancy: 64 years ³
- Multimorbidity and challenging behavior are common
- Only 18% of patients with ID received palliative care at end-of-life in UK ⁴



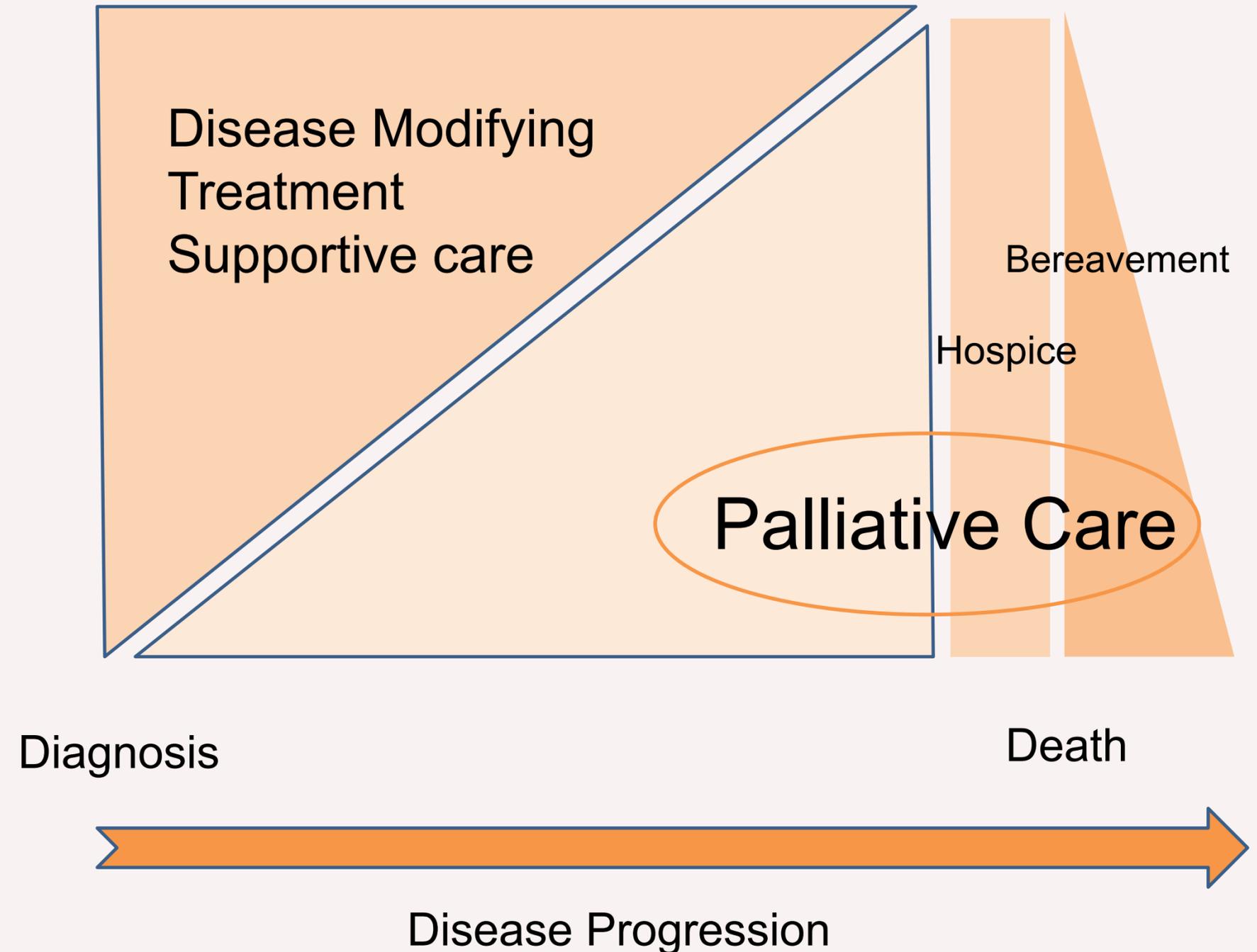
1.Census: 2020
2.American Association on Intellectual and Developmental Disabilities
3.Heslop et al 2014
4.Hunt et al 2020

Introduction

Palliative care (PC)

WHO Definition:

- Improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual
-is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.



Palliative Care & People with ID

Physical symptoms

- Most common symptoms: Fatigue (83%), drowsiness(65%), and decreasing intake (57%)¹
- 30% reported pain¹

Psychosocial Needs

- 16% of patients >50 years old with ID had anxiety / depressive symptoms²
- Carers: Higher level of psychological distress
 - Problem of “double” aging³
 - Caring of people with ID can put strains on family relationship⁴

1.Vrijmoeth et al 2016

2. Hermans et al 2013

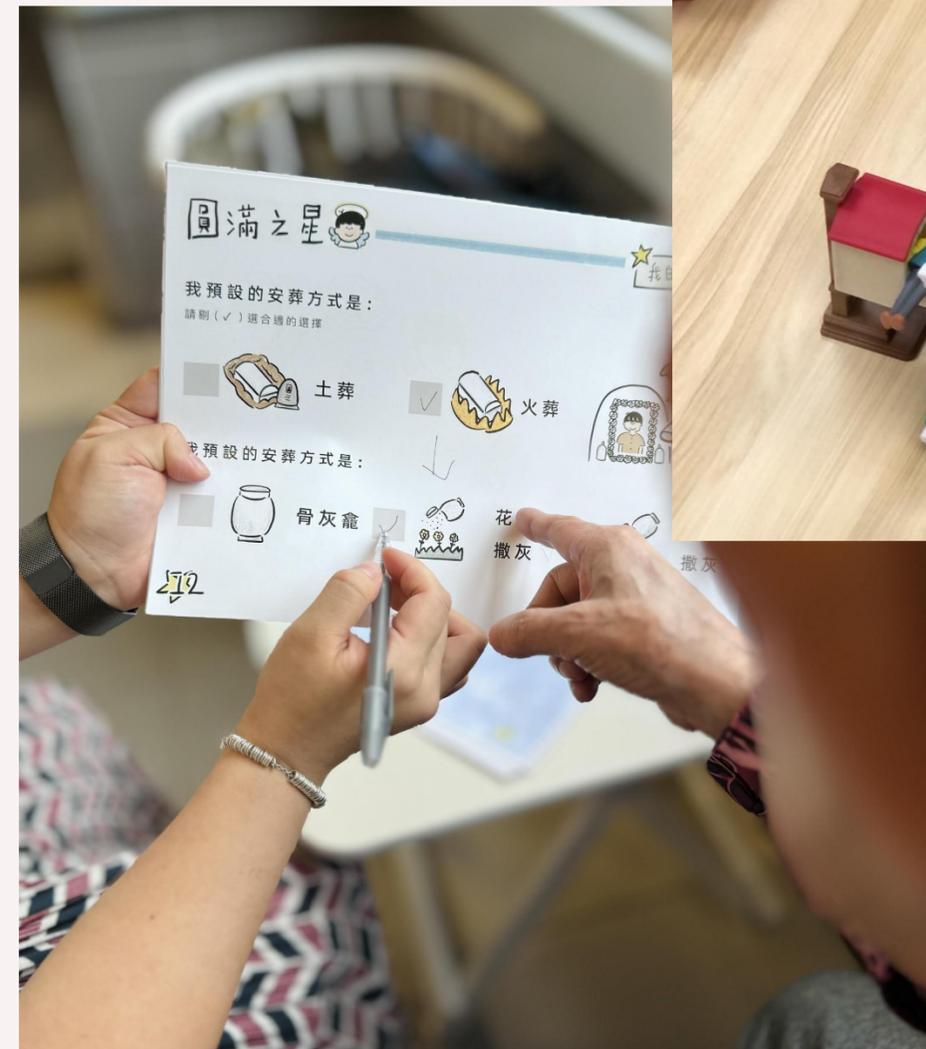
3 Mahon et al 2019

4.Taggart et al 2012

Palliative Care & People with ID

Advance Care Planning (ACP)

- It is safe to engage patients with ID to discuss end-of-life issues ¹
- People with ID can have partial or even full understanding of concepts of death ²
- Systemic review:
 - Elements of ACP: mainly decision-making and organizational policies
 - No effect studies, no studies on perspective of patients with ID
 - Conducive factor: good working relationships between professionals and relatives.
 - Obstructing factors: difficulties in recognizing palliative needs ; uncertainties among relatives and professionals about their roles and tasks in ACP ³



1.Stancliffe et al 2021
2.Chow et al 2017
3.Voss et al 2017

Palliative Care & People with ID

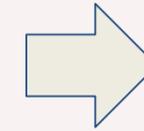
How is it related to
“Safety”?

Symptom Management

Enhance communication

Individualized care

Coordinated Care



↓ risk of compromised quality of life

Psychological Safety

Medication safety

Avoid misunderstanding

↓ risk of premature death

Challenges

Patient-based factors

- Communication problems
- Behavioral problems

Clinician-based factors

- Lack of knowledge
- Lack of experience
- Lack of clinical guidelines
- Lack of time

Carer-based factors

- Diagnostic shadowing
- Lack of knowledge about healthcare problems
- Misconceptions

Organizational factors

- Fragmented care



Access provided by Hospital Authority

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A multipronged approach to advancing palliative care for people with intellectual disabilities

[Kwok Ying Chan](#) ✉ • [Kwok Wai Tsang](#)

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PlumX Metrics

“Embracing the Setting Sun” Project

- Aim:

- To provide seamless delivery of palliative care with interface between the medical sector and social sector
- To provide holistic care to patients with disabilities throughout the illness trajectory



Multidisciplinary & Interdisciplinary Palliative Care Team



- Grantham Hospital PC Team
- Palliative Care Team doctor
 - Home Care Nurse
 - Nurse Consultant
 - Hospital medical social worker

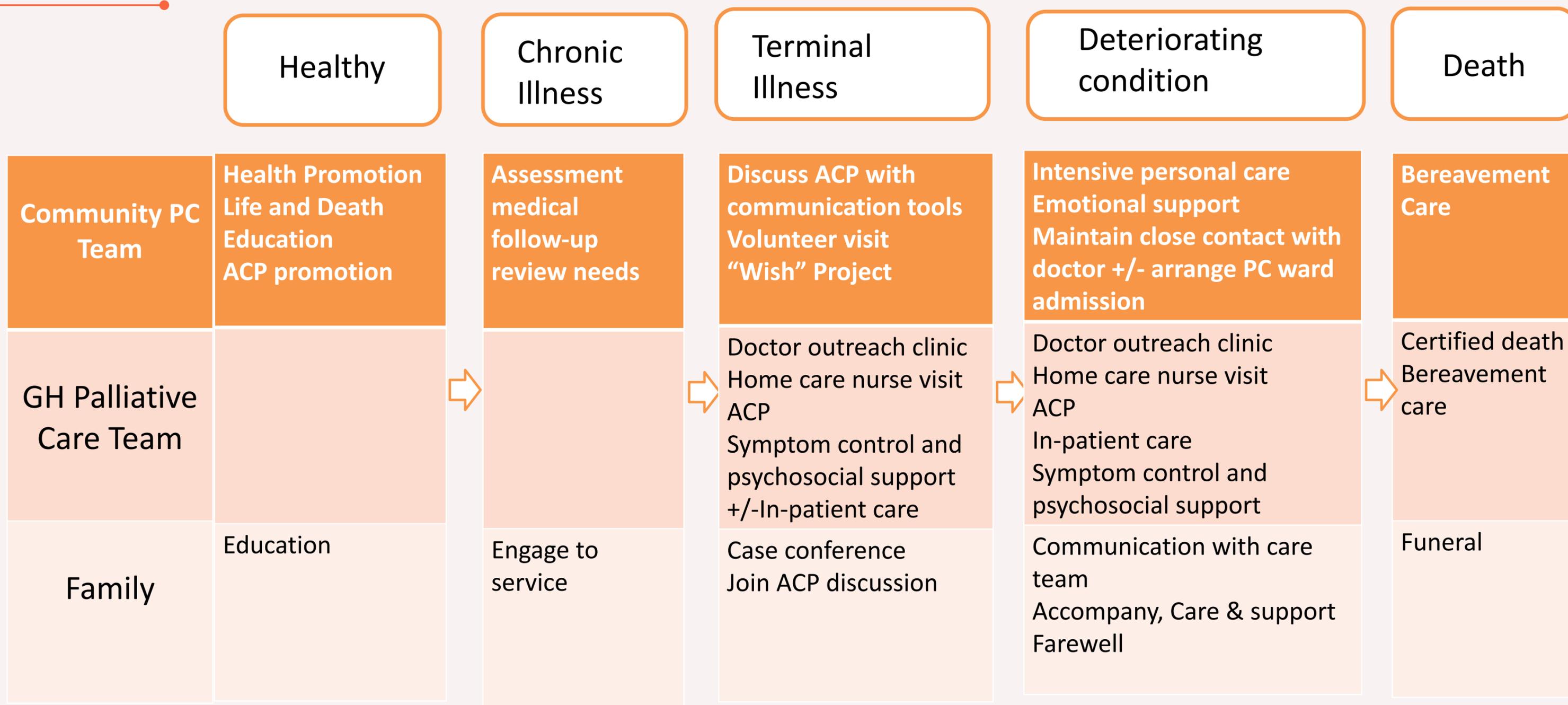


- Community PC Team in Jockey Club Rehabilitation Complex
- Link Nurse
 - Social Worker
 - Volunteers



Referral Criteria:

- Surprise Question: “would you be surprised if the patient were to die in the next year?”
- Repeated unplanned hospital admissions
- Remarkable deterioration in general condition
- Complex psychosocial needs



Outreach PC team

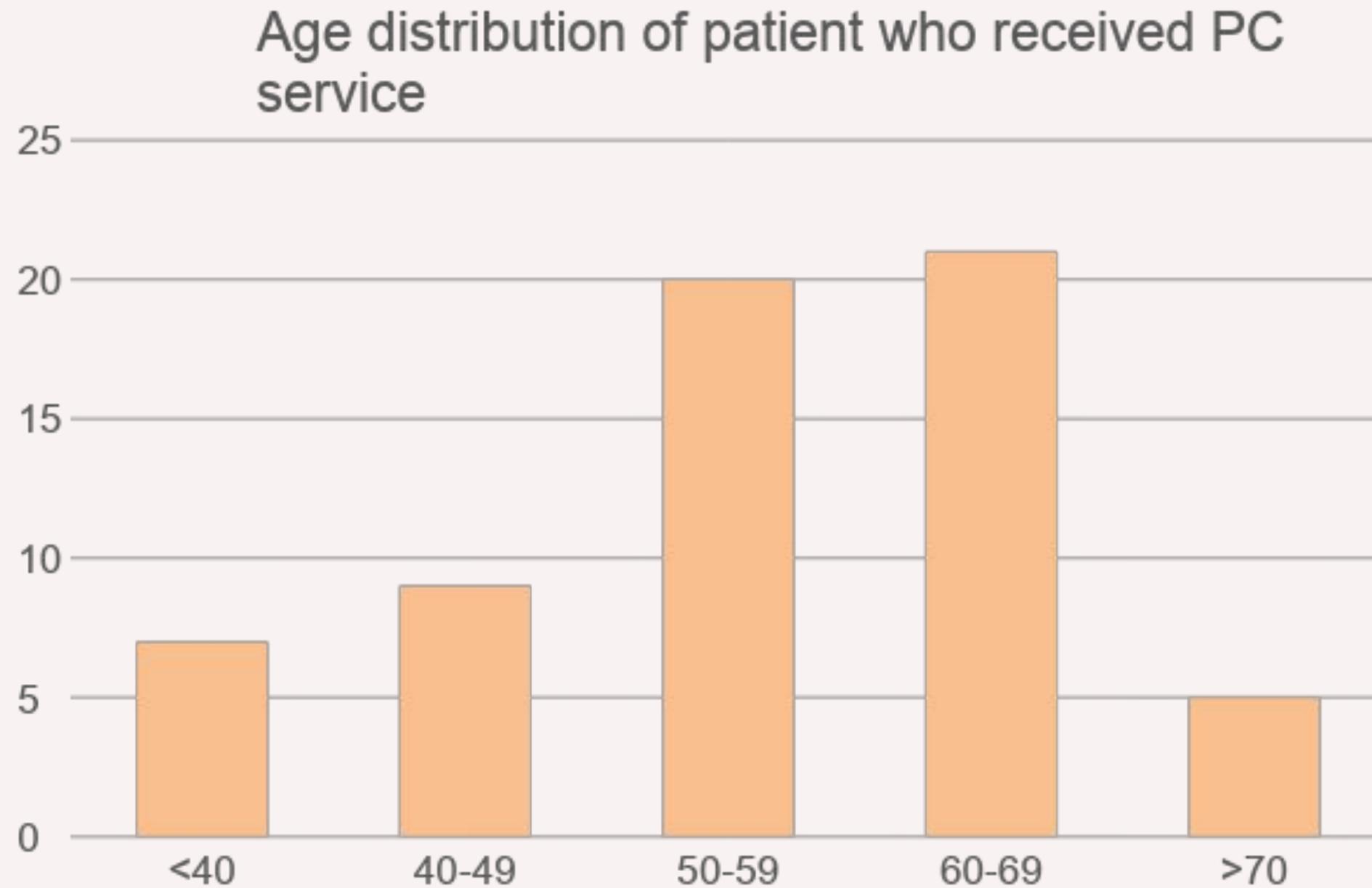
- Hospital PC team visit the patient at residential home
 - Familiar environment -> less stressful to patient
 - Care team available -> Clear communication between hospital and community PC team/staff
 - collateral information and instant support
 - enhances the skills transfer/sharing of knowledge



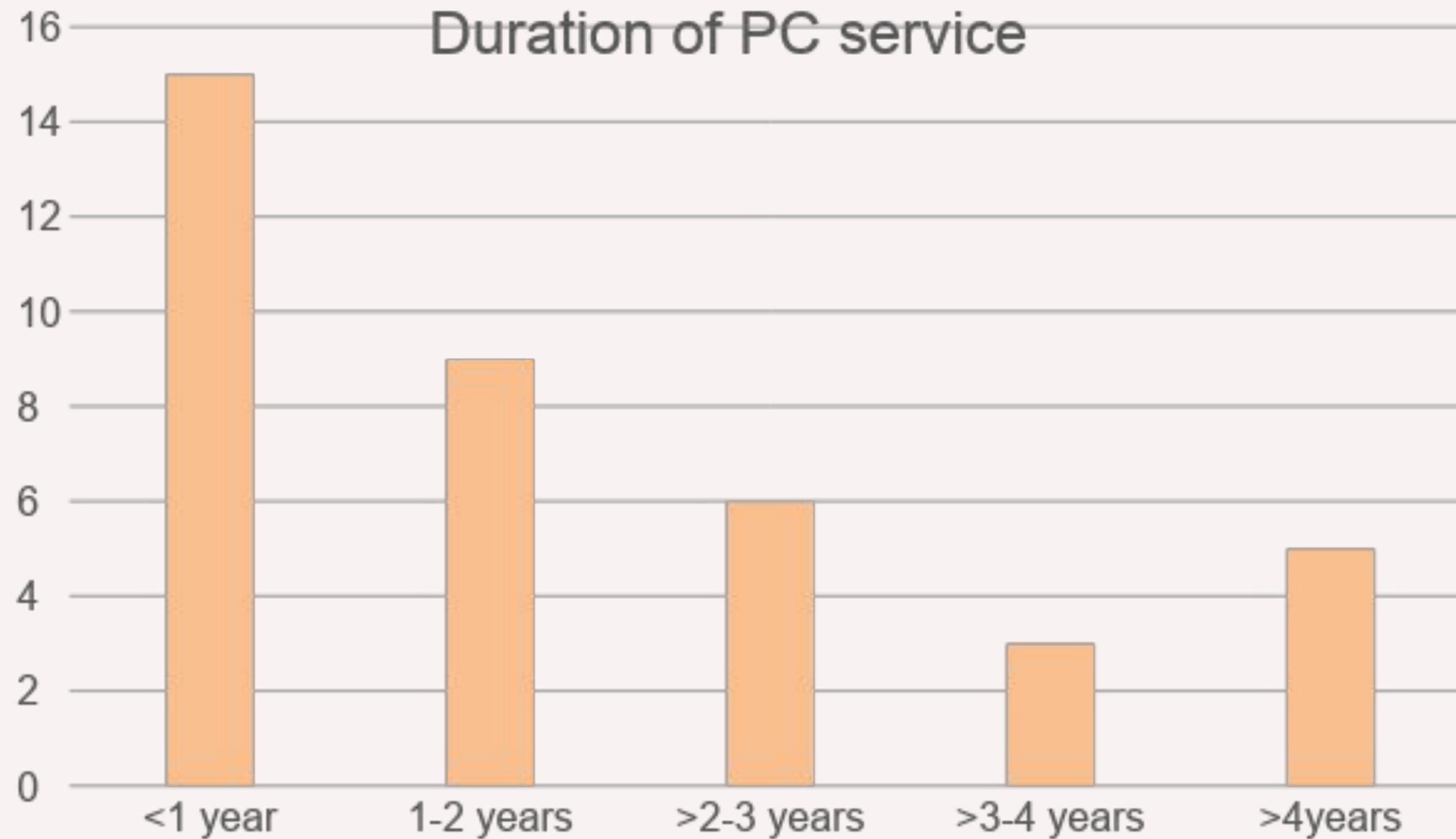
Retrospective review of ID patients referred for palliative care services

- Jan 2008 to Apr 2024
- Number of patients: 62 (38 patients passed away)
- 30 (48.4%) females; 32 (51.6%) males
- Duration of follow up: Median: 1 year 7 months
- Age of patients at time of referral:
 - Range: 21-75
 - Mean: 55.7 (SD 11.2)

Retrospective review of ID patients referred for palliative care services



Retrospective review of ID patients referred for palliative care services



Retrospective review of ID patients referred for palliative care services

- **Most common co-morbidities:**
 - Epilepsy: 32 (51.61%)
 - Cancer: 11 (17.7%)
 - Dementia: 8 (12.9%)
- **Number of symptoms:**
 - Mean: 2.39 (SD 1.8)
 - 3 most common symptoms:
 - Constipation: 59.68%
 - Fatigue: 50% (moderate fatigue: 11.29%)
 - Decrease appetite: 25.81%

Retrospective review of ID patients referred for palliative care services

Advance Care planning

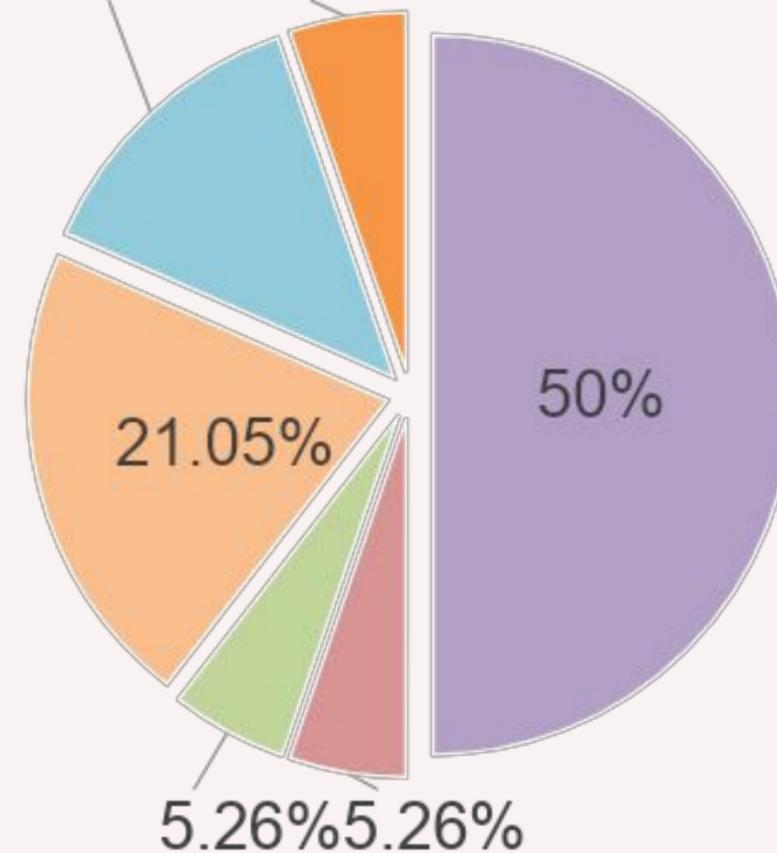
- No. of patients with ACP discussed: 42 (67.7%)
- Timing of ACP : mean 18.9 months before death
- Among patients who performed ACP discussion (n=42)
 - No. of patients decided not for cardiopulmonary resuscitation (CPR): 36 (85.7%)
 - Non-hospitalized Do-Not-Attempt-Cardiopulmonary-Resuscitation (DNACPR) signed:
27 (64.2%)
 - No. of patients decided for comfort feeding after ACP: 15 (35.7%)

Retrospective review of ID patients referred for palliative care services

- No. of patients passed away : 38
- Age at death:
 - Range: 24-74
 - mean: 58 (SD 11.03)

Cause of death (n=38)

13.16% 5.26%



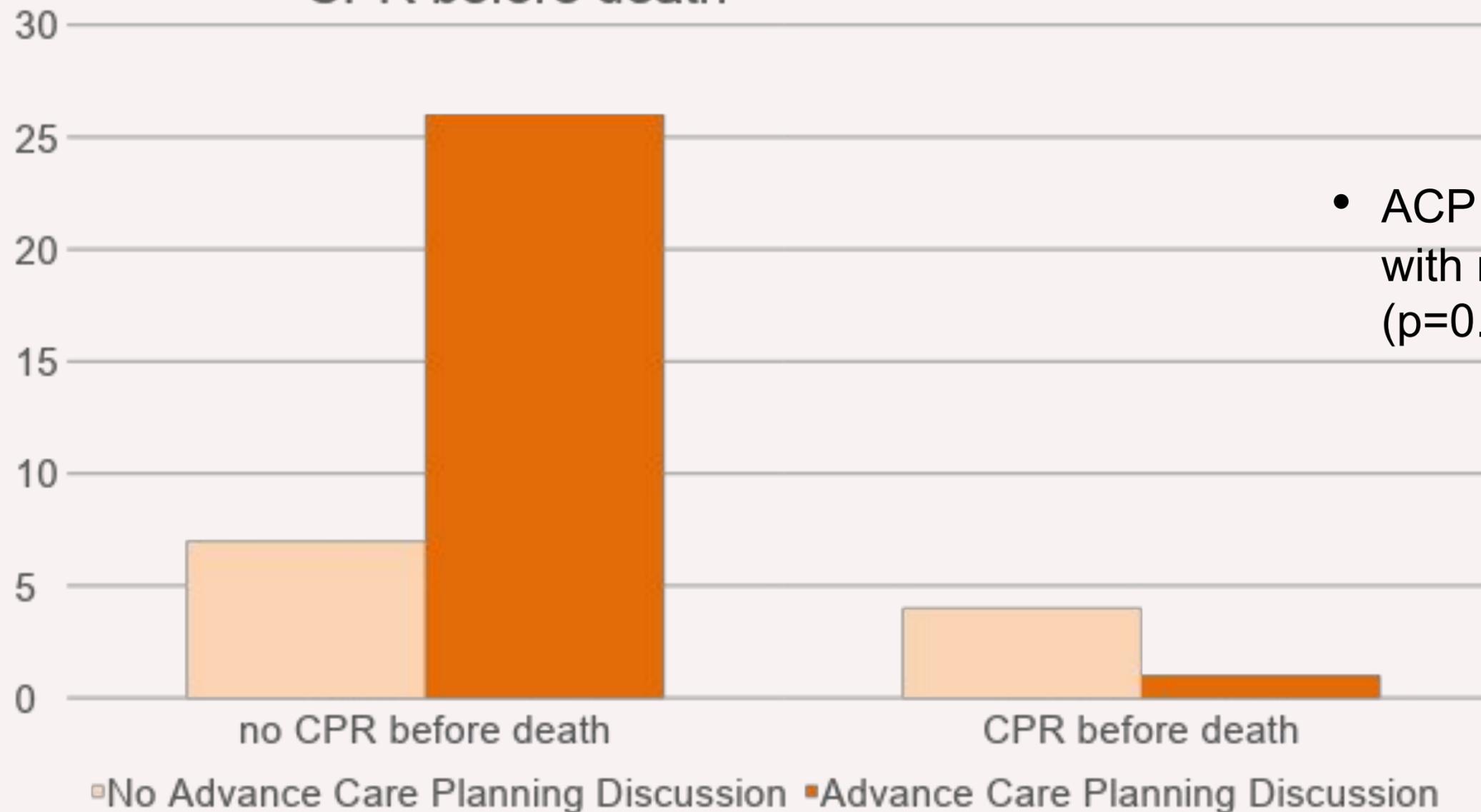
- Pneumonia
- COVID
- Other infection
- unknown

Retrospective review of ID patients referred for palliative care services

- 33 (86.8%) passed away without performing CPR
- No. of patients passed away in GH palliative care unit : 9 (22.37%)
- No. of patients who had ICU admission in last 30 days: 1 (2.63%)
- No. of patients who had more than 1 AED admission in last 30 days: 7 (18.4%)
- No of patients who had more than 1 hospital admission in last 30 days : 12 (31.5%)

Retrospective review of ID patients referred for palliative care services

Relationship between Advance Care Planning and CPR before death



- ACP discussion was associated with no CPR before death (p=0.0069)

Conclusion

- People with intellectual disabilities have complex palliative care needs
- Medical-Social Collaboration is feasible way to deliver palliative care service to patients with intellectual disabilities
- It facilitates ACP discussion and enhances patient-centered care

Our Team



You matter because you are you, and you matter to the last moment of your life. We will do all that we can, not only to help you die peacefully, but also to live until you die.

Dame Ciceley Saunders



Thank You