

Follow Up Study of 15 Consecutive Children with Anti NMDAR Encephalitis

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ePoster: P6.015

Goal

Evaluate the function of 13 children with anti NMDAR encephalitis after discharge from an acute pediatric rehabilitation hospital with a telephone survey.

Subjects

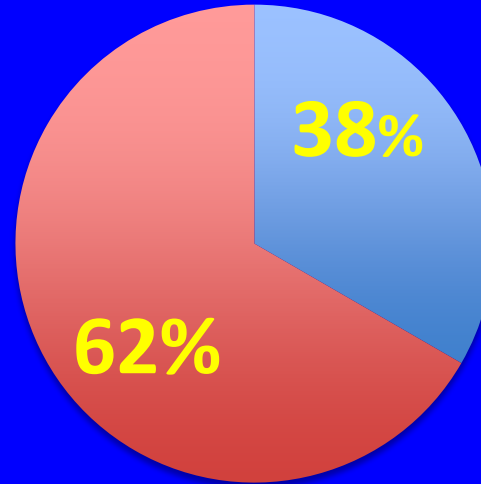
- N = 13
- Mean age at admission = **10.9 y** (2.1 – 18 yo)
- Consecutive admissions to Blythedale, a Children's Specialty Hospital
- Intensive inpatient rehabilitation for all patients

Mortality

$$1/13 = 8\%$$

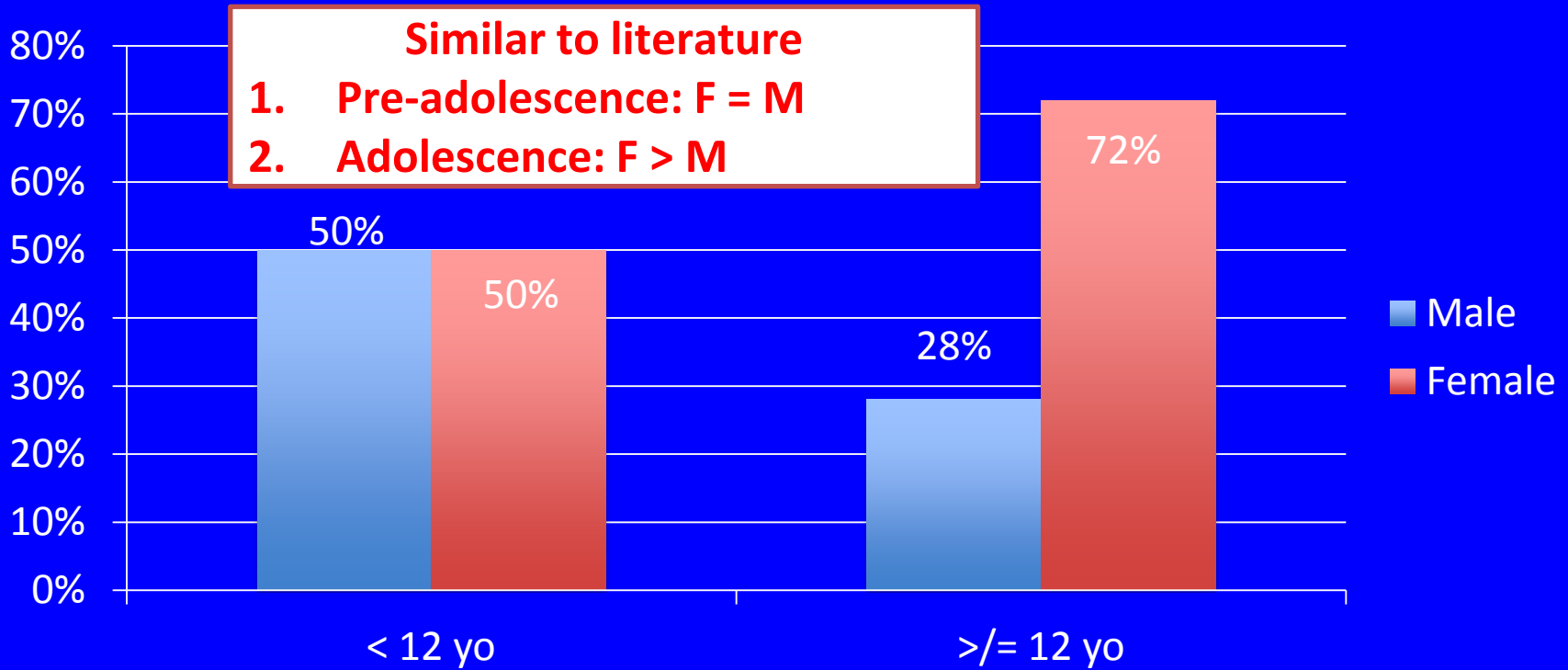
Gender Percent

N = 15



■ Male ■ Female

Gender and Age



N = 13

Length of Stay

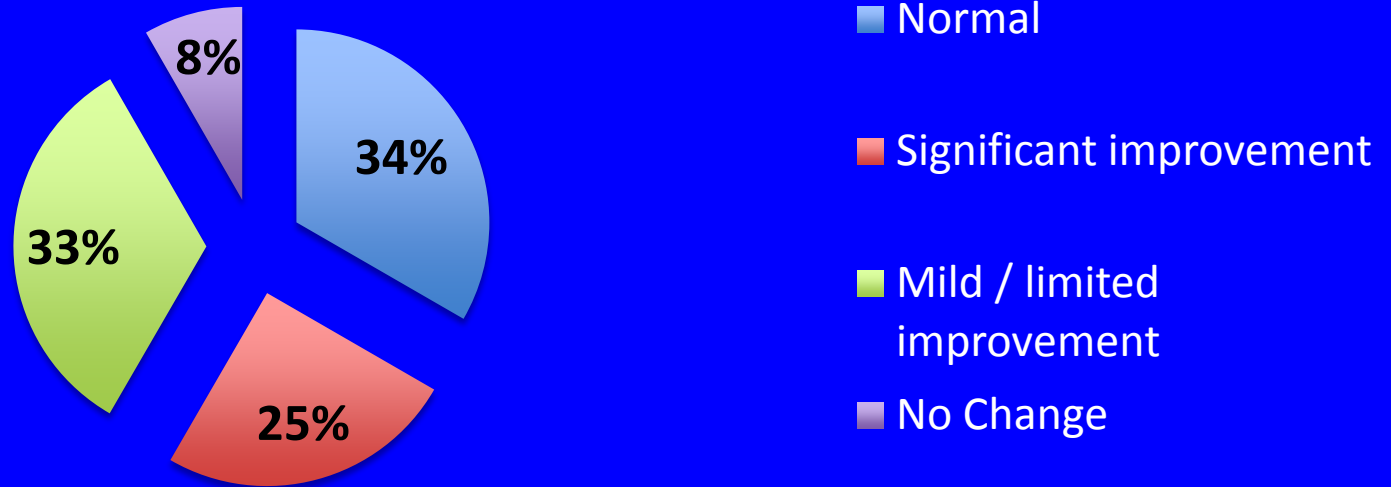
- Mean LOS: **5.6 months**
- Range: **0.7 – 16.8 months**

FOLLOW UP STUDY

- 1st: \geq ~3 months post discharge. N = 12
 - Mean: 10.8 months
 - Range: 2.3 – 27 months
- 2nd: 12 months after 1st post discharge survey
- Telephone survey with parents/caregivers

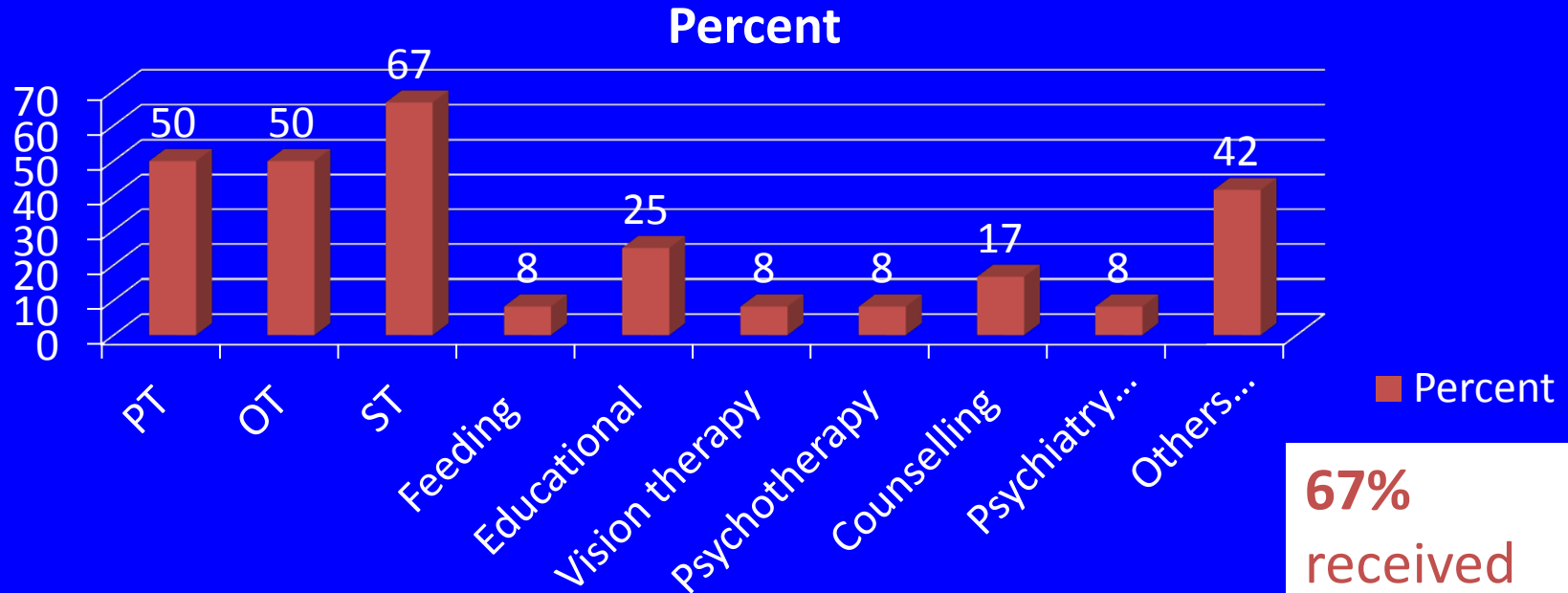
Function at 1st Follow Up

Percent



N = 12 survivors

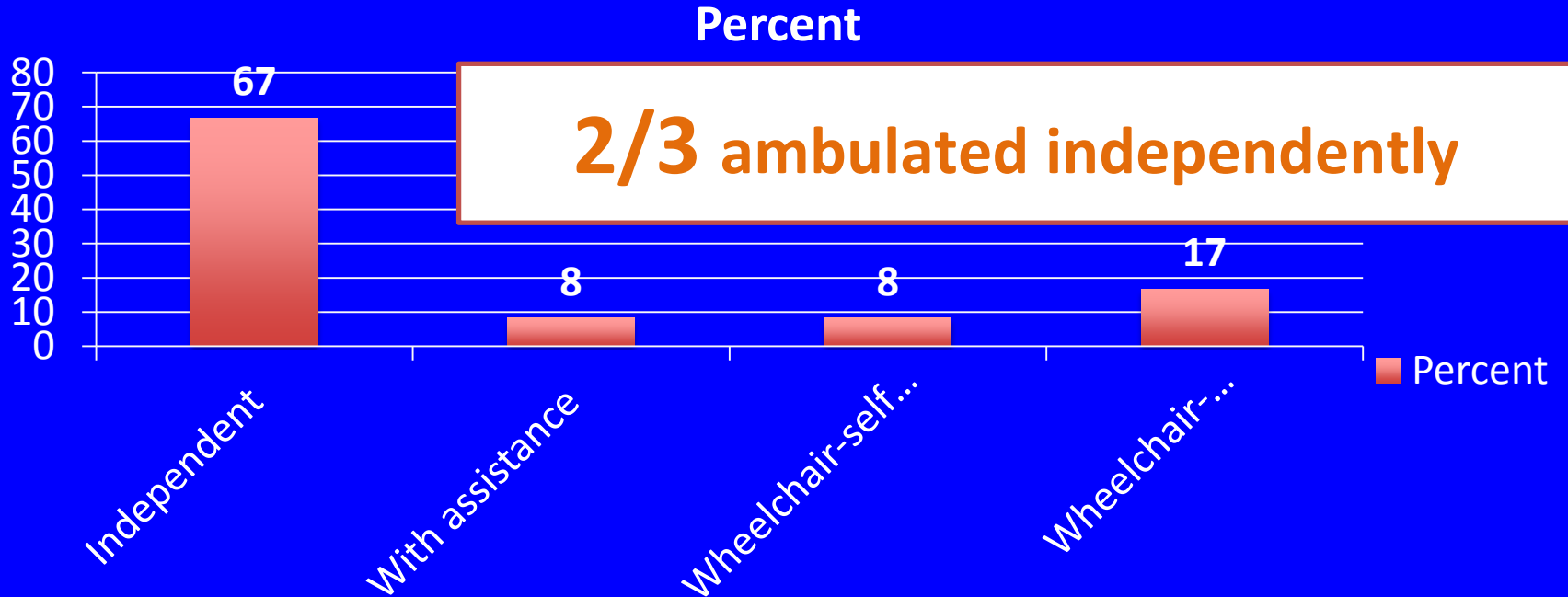
Percent Receiving Therapy at 1st FU



N = 12 survivors

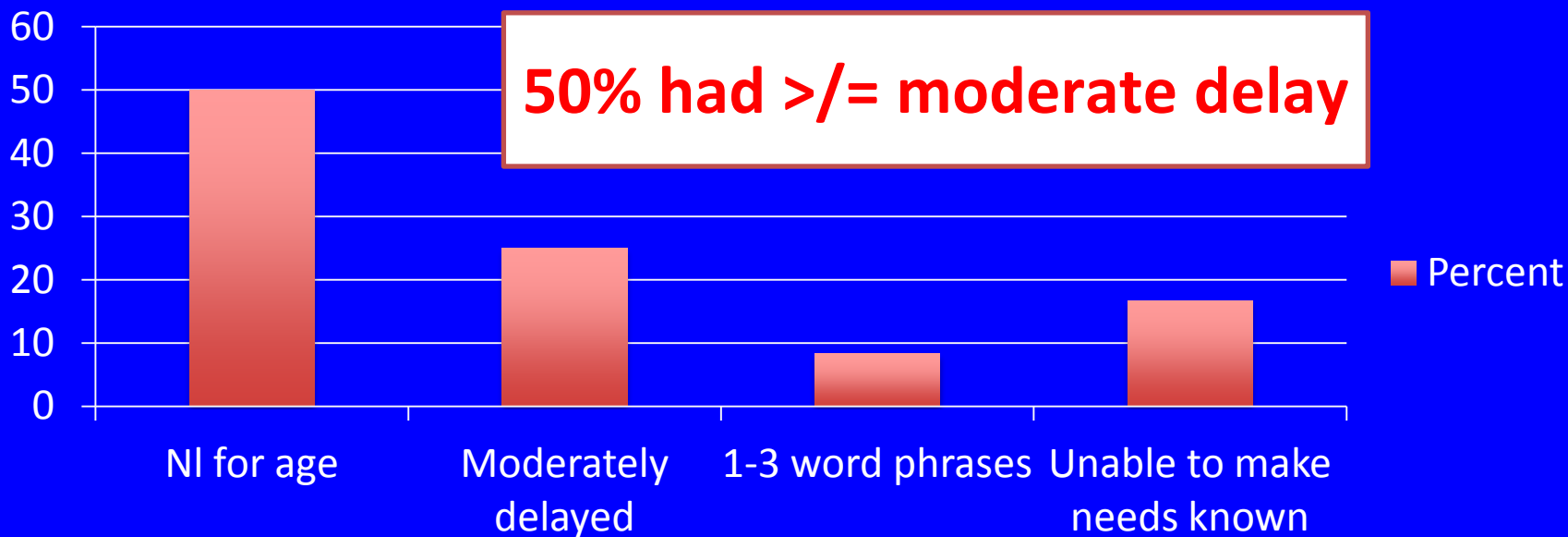
67%
received
therapy post
discharge

Gait Status at 1st F/U



Expressive Language at 1st F/U

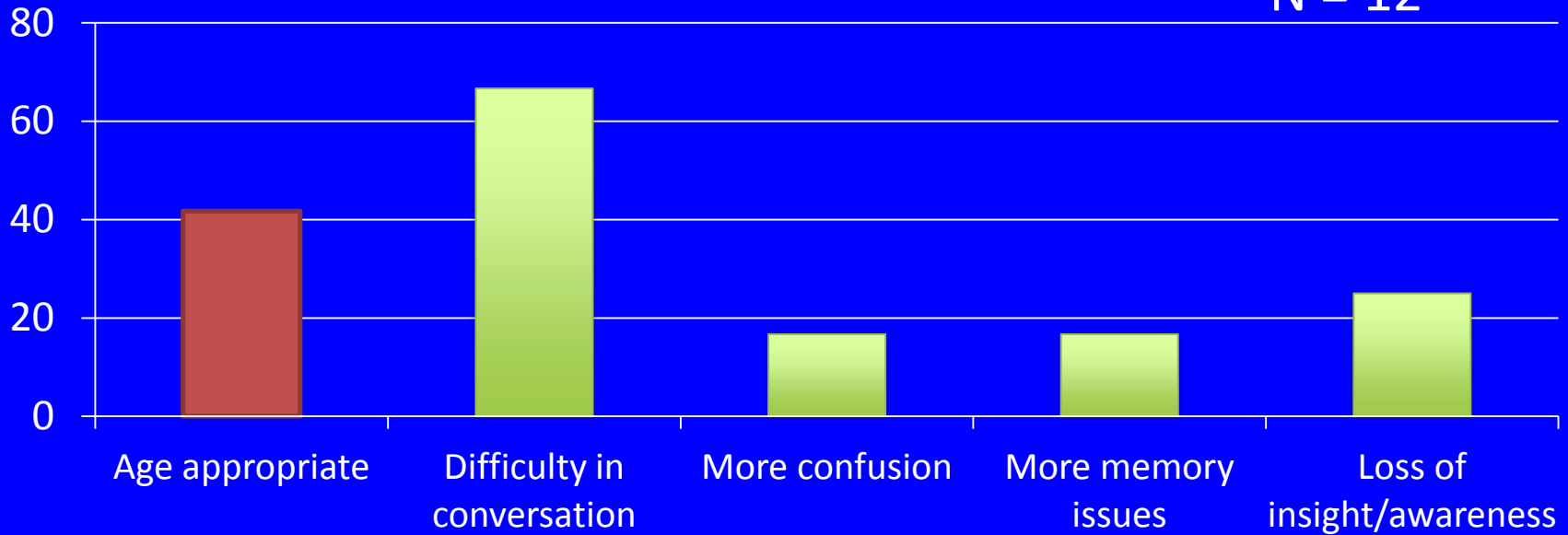
Percent



Receptive Language and Cognitive Function at 1st F/U

Percent

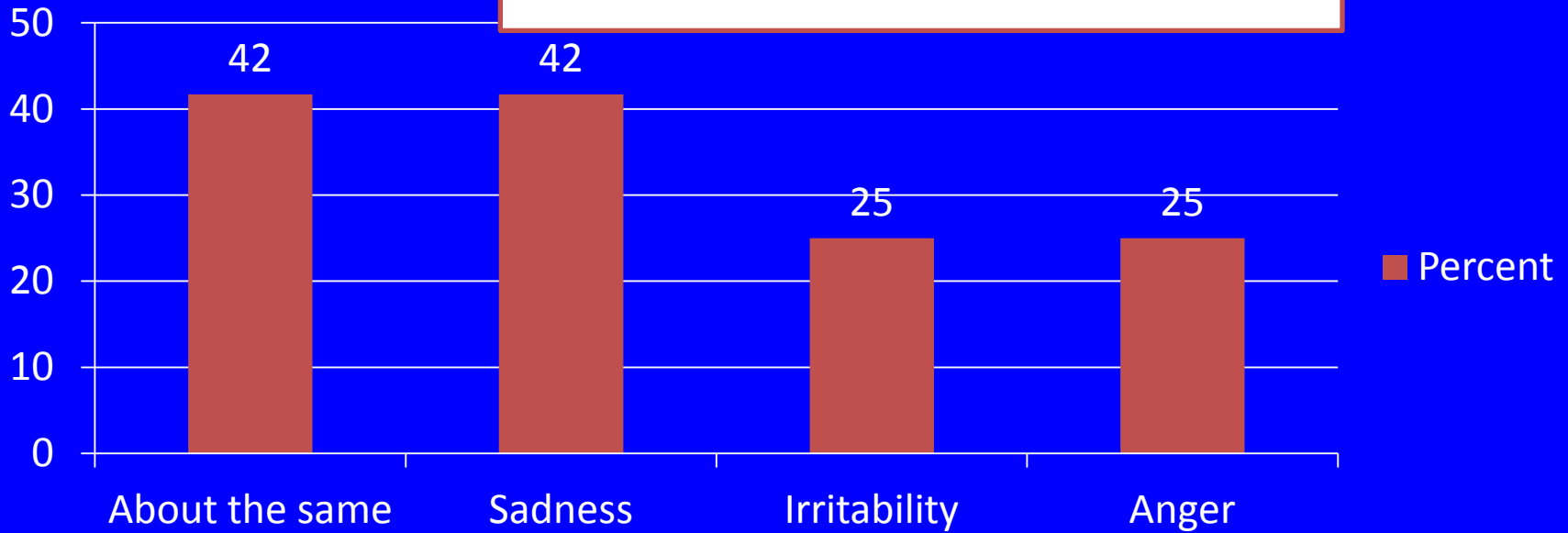
N = 12



60% had \geq some delay

Mood at 1st F/U

58% had change in mood



N = 12; ≥ 1 mood problem

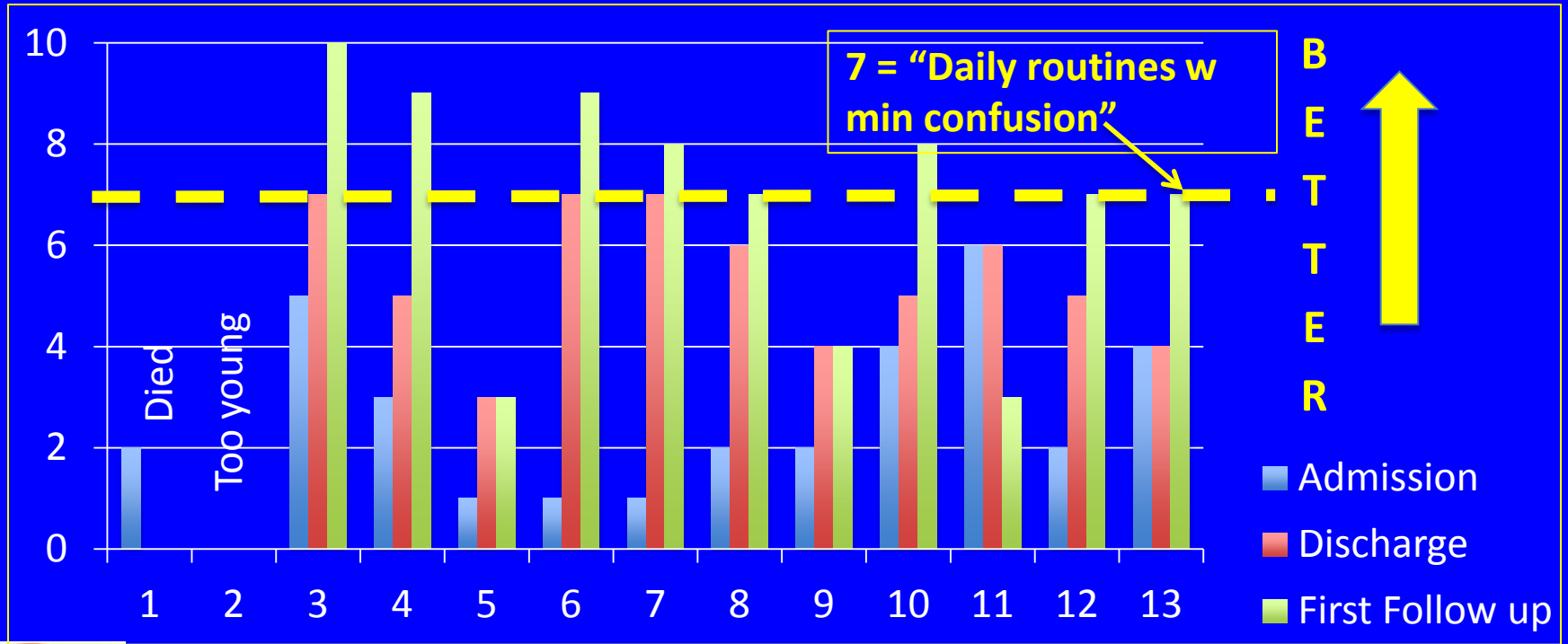
Blythedale Day Hospital Program

- Intensive therapies + special education
- Post in-patient discharge
- **50%** of discharged patients attended Day Hospital Program

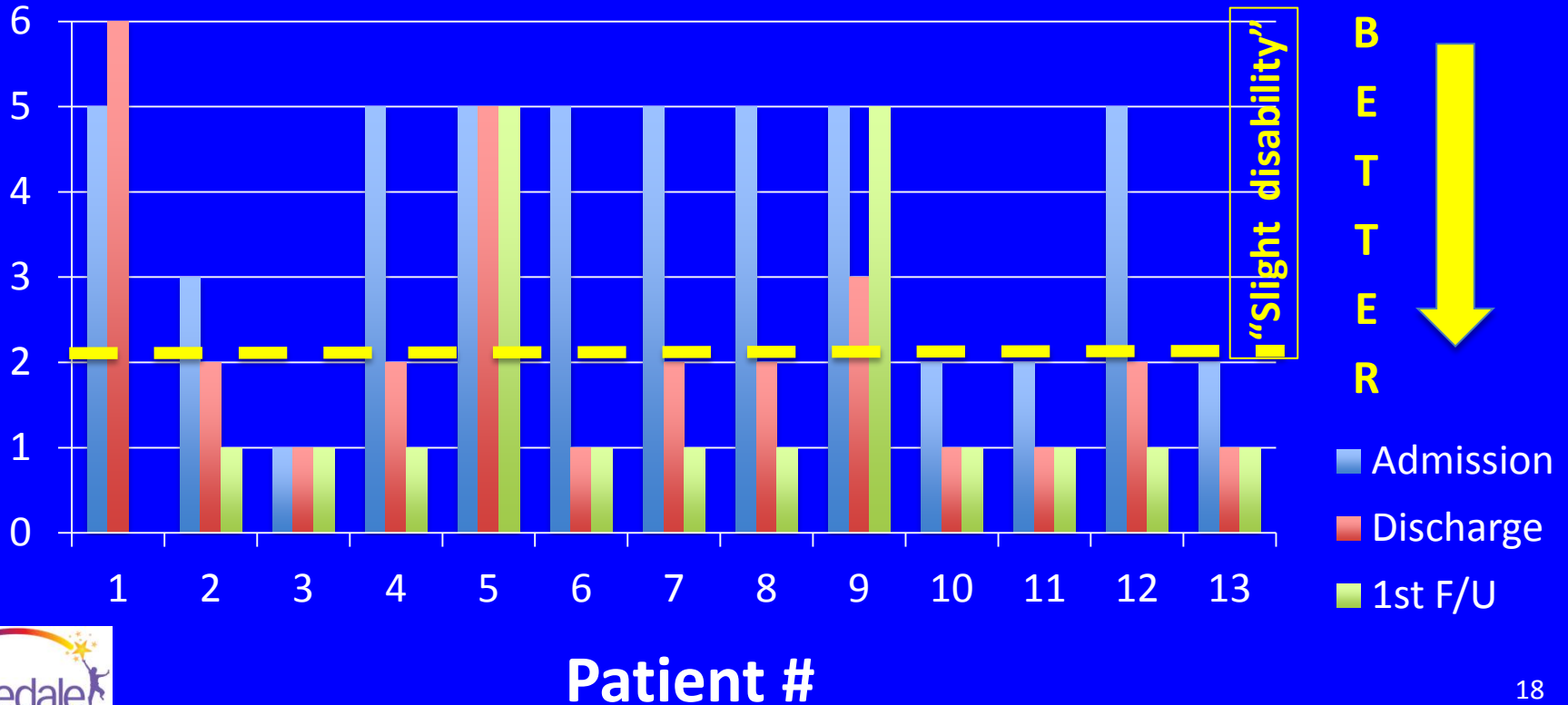
INDICATORS of Function

- Rancho Los Amigos
- Pediatric modified Rankin
- Gross Motor Function Scale

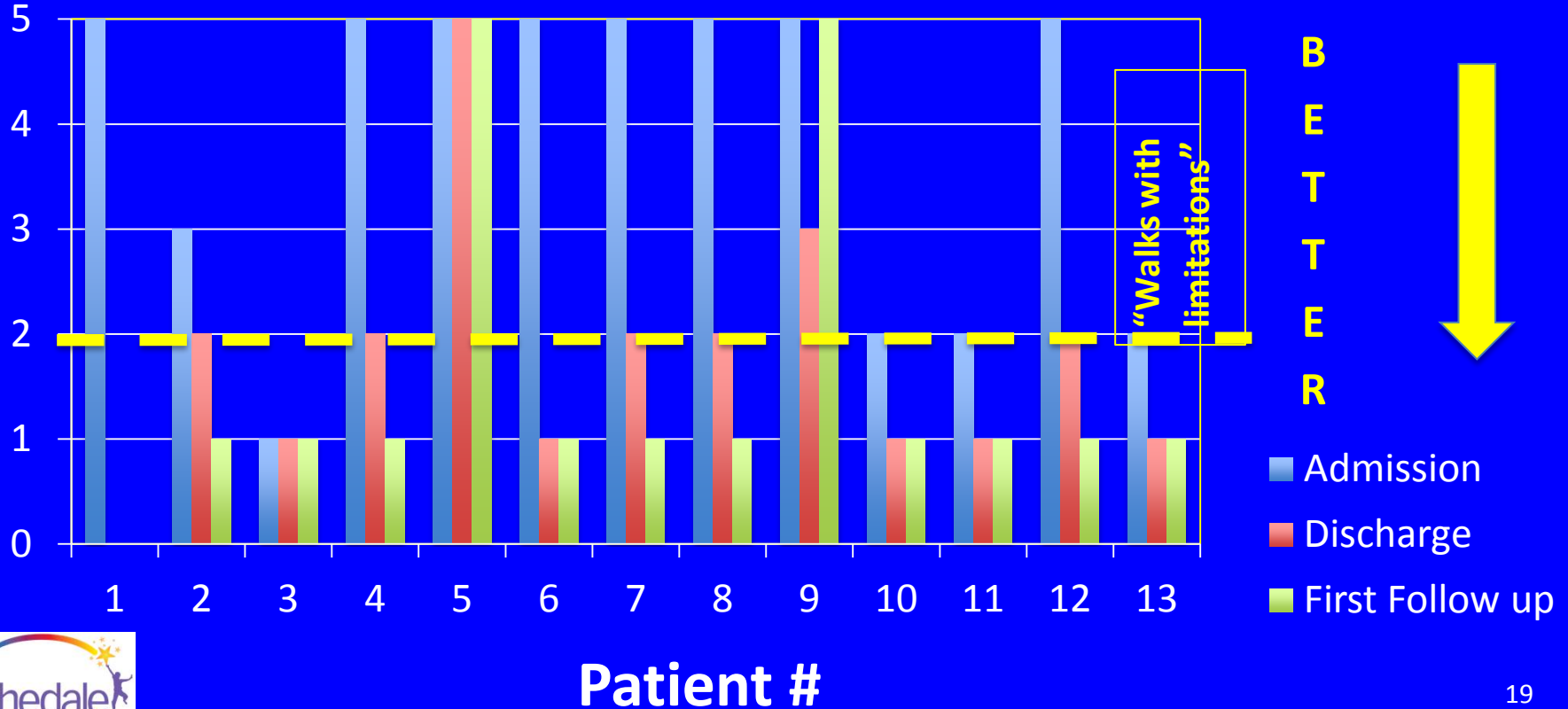
Rancho Los Amigos



Pediatric modified Rankin Scale



Gross Motor Function Scale



Conclusions

- Some pediatric patients with ANMDARE have a very prolonged, complicated course
- In cohort of 13 children
 - **1/3** had significant residual functional problems
 - **2/3** were still receiving therapy \geq 3 months post d/c
 - Intensive inpatient rehabilitation is essential
 - Many children continued to improve post discharge

Summary

Children with ANMDARE admitted for intensive rehabilitation have a high probability of significant residual educational, language, motor, and emotional issues. They will need continuing support services after discharge.

Recommendations

- Suspect the diagnosis
- Start early, aggressive treatment
- Use multimodality immunotherapy
- Refer for inpatient acute rehabilitation

For Further Information

- Blythedale Children's Hospital: www.Blythedale.org
- Jay E. Selman, MD: JSelman@Blythedale.org 914.831.2480
- Presentation, Handout, Bibliography:

<http://www.blythedale.org/research-case-archive>

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Our Research Team

- IT Team:
 - Roni Amiel, CIO
 - Vinod Jacob
- Nicole Martini, LCSW
- Christopher Rackley, PsyD
- Josephine Kuhl, MD
- Kathy Silverman, DO

Appendices

Rancho Los Amigos Levels of Cognitive Functioning

- **Level 1:** No response, person appears to be in deep sleep
- **Level 2:** Generalized response, person reacts inconsistently, not directly in response to stimuli
- **Level 3:** Localized response, reacts inconsistently, directly to stimuli
- **Level 4:** Confused/Agitated, person is extremely confused, agitated
- **Level 5:** Confused-Inappropriate/Non-Agitated, person is confused and responds inaccurately to commands
- **Level 6:** Confused-Appropriate, Person is confused, responds accurately to commands
- **Level 7:** Automatic-Appropriate, person goes through daily routine with minimal confusion
- **Level 8:** Purposeful-Appropriate, person has functioning memory, responsive to environment, may display depression
- **Level 9:** Purposeful-Appropriate, goes through daily routine aware of need for stand-by assistance, depression may continue
- **Level 10:** Purposeful-Appropriate/Modified Independent, goes through daily routine but may require more time or compensatory strategies, periodic depression may occur.

Rancho Los Amigos

Pediatric modified Rankin Scale

Score Description

0 No symptoms at all

1 No significant disabilities despite symptoms in clinical examination; age appropriate behaviour and further development

2 Slight disability; unable to carry out all previous activities, but same independence as other age- and sex-matched children (no reduction of levels on the gross motor function scale)

3 Moderate disability; requiring some help, but able to walk without assistance; in younger patients adequate motor development despite mild functional impairment (reduction of one level on the gross motor function scale)

4 Moderately severe disability; unable to walk without assistance; in younger patients reduction of at least 2 levels on the gross motor function scale

5 Severe disability; bedridden, requiring constant nursing care and attention

6 Dead

Gross Motor Function Scale

LEVEL I - Walks without Limitations

LEVEL II - Walks with Limitations

LEVEL III - Walks Using a Hand-Held Mobility Device

**LEVEL IV - Self-Mobility with Limitations; May Use Powered
Mobility**

LEVEL V - Transported in a Manual Wheelchair

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