Follow Up Study of 15 Consecutive Children with Anti NMDAR Encephalitis

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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

\[ \frac{1}{13} = 8\% \]
Gender

Percent

N = 15

38% Male
62% Female
Gender and Age

Similar to literature
1. Pre-adolescence: F = M
2. Adolescence: F > M

N = 13
Length of Stay

• Mean LOS: 5.6 months

• Range: 0.7 – 16.8 months
FOLLOW UP STUDY

• 1st: >/= ~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

N = 12 survivors

Percent

- Normal: 34%
- Significant improvement: 25%
- Mild / limited improvement: 33%
- No Change: 8%
Percent Receiving Therapy at 1st FU

N = 12 survivors

67% received therapy post discharge
Gait Status at 1\textsuperscript{st} F/U

\begin{itemize}
\item Independent: 67\%
\item With assistance: 8\%
\item Wheelchair-self: 8\%
\item Wheelchair-\ldots: 17\%
\end{itemize}

\textbf{2/3 ambulated independently}

N = 12 survivors
Expressive Language at 1st F/U

- 50% had ≥ moderate delay
- N = 12
Receptive Language and Cognitive Function at 1st F/U

60% had >/= some delay

N = 12

Percent

Age appropriate  Difficulty in conversation  More confusion  More memory issues  Loss of insight/awareness

0  10  20  30  40  50  60  70  80

N = 12
Mood at 1st F/U

58% had change in mood

- About the same: 42%
- Sadness: 42%
- Irritability: 25%
- Anger: 25%

N = 12; >/= 1 mood problem
Blythdale 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

7 = “Daily routines w min confusion”

Died Too young

B E T E R

Admission
Discharge
First Follow up
Pediatric modified Rankin Scale

Patient #

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<thead>
<tr>
<th>Patient</th>
<th>Admission</th>
<th>Discharge</th>
<th>1st F/U</th>
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"Slight disability"
Gross Motor Function Scale

Patient #

1. Admission
2. Discharge
3. First Follow up

“Walks with limitations”

B E T T E R

Patient #
Conclusions

• Some pediatric patients with ANMDARE have a very prolonged, complicated course

• In cohort of 13 children
  – \(\frac{1}{3}\) had significant residual functional problems
  – \(\frac{2}{3}\) 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

- Blythededale Children’s Hospital: [www.Blythedale.org](http://www.Blythedale.org)
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  [http://www.blythedale.org/research-case-archive](http://www.blythedale.org/research-case-archive)

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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.
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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