A Subtype of Functional Neurological Disorder; Humpty Dumpty Syndrome: A Longitudinal Examination of Wellness after Diagnosis

Kelly Nye, PhD, Michel Berg, MD, Jennifer Farah, PhD, John Langfitt PhD, Nancy Shinder LMSW

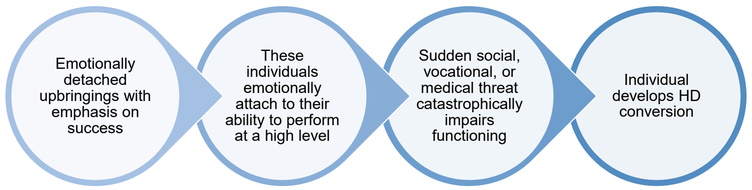
Purpose

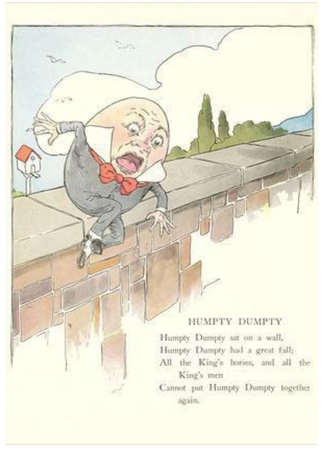
(1) To determine the relative frequency and characteristics of patients with Humpty Dumpty Syndrome at an epilepsy center
(2) To determine the perceived factors contributing to their status ~20-years after their admission

Introduction

- Subtypes of patients with psychogenic nonepileptic attacks are not typically defined in the literature.
- Charles Ford (1978) first coined the term "Humpty Dumpty Syndrome" to explain a type of "disability neurosis' that he observed in eight male patients.
- Humpty Dumpty (HD) is a variant of a classic conversion disorder, distinguished by specific traits associated with a person's familial upbringing being emotionally detached (Ford, 1978).
- Ford (1978) described that interventions for this need to be prophylactic before symptoms become entrenched and resistant to treatment.

Conceptualization of Timeline and Biopsychosocial factors that contribute to HD Onset





Inclusion Criteria

- Were in a productive vocation
- Experienced a perceived health crisis per verbal report
- Loss of their vocation due to persistent PNEA

Exclusion criteria

- Emotional stressors associated with the onset of their PNEA
- Dx of somatization disorder
- Co-morbid epilepsy
- Other types of non-electrical events
- No definitive diagnosis for their attacks
- Hx/Dx of a major psychiatric disorder

Humpty Dumpty seems an apt name for this disorder. In the English Civil War (1642-49) "Humpty Dumpty" was the name of a powerful cannon that fell to the ground because it was over laden; it could not be repaired. Patients with the Humpty Dumpty syndrome have an analogous commanding facade that acutely collapses when overburdened. Standard treatment attempts are unsuccessful. In contrast to the nursery rhyme, we hope that with accurate diagnosis modern day 'surgeons' are successful with restoration.

Methods

Sample:

- *Initial sample:* 167 individuals (male = 50, female = 117) were diagnosed with PNEA between years 2002-2004 using video-EEG long-term monitoring (LTM) at URMC. 12 were identified as having the HD subtype.
- *~20 year follow-up sample*: 12 total: 11 females and 1 male who were individuals identified as meeting criteria for Humpty Dumpty Syndrome.

Design/Methods:

- Design 1: Single-center retrospective medical record review
  - Retrospective medical record review was conducted between the years 2004-2007 and identified 12 individuals diagnosed with PNEA who met the inclusion criteria for Humpty Dumpty Syndrome.
- Design 2: Single-center retrospective medical record review and longitudinal design
  - Retrospective medical record review was conducted (2022) to review H&P during admissions, follow-up outpatient neurology notes, diagnoses, and current primary care providers.
  - Primary care doctors of all 12 patients were contacted with goal of enrolling patients into current study.
  - After patient's consented to study, the goal was to follow up with a combination of instruments and close-ended questions.
  - Identified instruments included: WHOQUAL-BREF and close-ended questions: Close-ended questions included:
    - Current employment status
    - Present occupation
    - Current PNEA symptoms, and frequency/intensity of events
    - Other chronic medical conditions being treated
    - Participants perception of their PNEA diagnosis
    - How they decided to follow-up with treatment post-discharge from LTM
    - Whether these treatments were perceived as helpful or unhelpful

Results

Results of Initial Record Review: Of the 167 individuals diagnosed with PNEA who were admitted for EEG LTM between the years 2002-2004, 12 met the criteria for Humpty Dumpty Syndrome:

- 11 were females and 1 was male
- Attack onset occurred between 17 and 56 years old (median 32 years old)
- 8 were married or in a committed relationship and 4 were single
- Attack semiology:
  - 5 had major motor movements (i.e., nonepileptic seizures characterized by full body convulsions).
  - 6 had withdrawn states (i.e., staring, unresponsiveness).
  - 1 had both behavioral patterns in different events.
  - 9 were victims of physical/emotional/sexual abuse.
  - 2 had presence of another individual in their life with seizures.
  - 8 reported an emotionally deprived childhood environment.
  - 7 actively engaged in social activities, 5 did not endorse positive healthy social life.

Results of the ~20 year follow-up: Of the 11 original patients

- 2 are deceased.
- 5 participants did not have correct PCP listed in chart, thus we were unable to include them in the study.
- 2 declined participation after contact by researcher.
- 2 did not return communications after consent was obtained.

Conclusion

- *Aim #1*: We were able to conclude that within our inpatient LTM EEG unit, that, 7% of our PNEA patients between the years 2002-2004 met the criteria for Humpty Dumpty Syndrome.
- *Aim #2*: Very long term follow-up of this population is challenging. In our sample, we were unable to determine perceived factors contributing to their current status ~20-years after their admission due to lack of recruitment.

Discussion

- Humpty Dumpty Syndrome is characterized by hard-working, emotionally detached individuals who become functionally disabled after a perceived health crisis, manifesting into a functional neurological disorder (specifically PNEA in our sample).
- Further study of these individuals post-discharge to understand the processes that were either helpful or unhelpful in their recovery so that effective interventions can be determined and provided to these patients soon after a diagnosis is made.

References
Ford, Charles (1978). A type of disability neurosis: The Humpty Dumpty Syndrome. The International Journal of Psychiatry in Medicine, 8(3), 285-94. https://doi.org/10.2190/MG4Q-BKKC-UF12-0F0F

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