Caring for the Caregiver
Skills Validation, a Pilot Project
Farrah Jones, BS, RRT, CRA
Robert Warren, MD

Disclosure Information
AACDPM 70th Annual Meeting | September 20-24, 2016

Speaker Name: Farrah Jones, BS, RRT, CRA
Robert Warren, MD

Disclosure of Relevant Financial Relationships
I have no financial relationships to disclose.

Disclosure of Off-Label and/or investigative uses:
I will not discuss off label use and/or investigational use in my presentation

Introduction
• Having a child with a neurodisability is a life-altering event
• Having a secondary chronic pulmonary condition adds physical and psychological burden
• Pulmonary dysfunction is progressive
Evolution Of Chronic Lung Disease In Children With Neurodisability

- Impaired cough and retained secretions
- Aspirated secretions from dysphagia and GER
- Respiratory infection / atelectasis
- Bronchiectasis / pulmonary dysfunction
- Diminished oxygenation
- Alveolar hypoventilation and CO₂ retention

How Do They Do It???

- Nutrition
- Activities of daily living
- PT/OT
- Medications
- Respiratory care

Respiratory Care

- Ability to monitor and assess pulmonary symptoms
- Knowledge of respiratory medications
- Technical expertise with respiratory devices
- Ability to evaluate response to therapy
Meet one of our patients

Diagnoses

• Premature Birth
• Traumatic Delivery Producing Asphyxia
• Partial Cervical Spinal Cord Injury
• Grade 4 Bilateral Intraventricular Hemorrhage
• Hydrocephalus
• Severe Developmental Delay
• GE Reflux and Dysphagia
• Chronic Aspiration
• Recurrent Pneumonia And Atelectasis
• Respiratory Insufficiency

Respiratory Therapies

• Continuous Mechanical Ventilatory Support
• IPV with albuterol and saline
• In/exsufflation TID
• Flovent 220 MDI 2 Puffs Bid
• Tracheal Suction PRN
How do we help?

- Knowledge is power!
- Knowledge results in CONFIDENCE
  - Ease anxiety
  - Optimize treatments
  - Save time

End Result

- Proper respiratory care carried out in the most time efficient manner results in more time for all other activities, including rest and relaxation!
- Nothing improves the caregiver’s psyche like SUCCESS!
- Skills Validation is a way to accomplish this goal for our caregivers

What is skills validation

- Definition: “A regularly scheduled assessment, usually annual, of the competence of staff by administrative personnel of a health care institution; the purpose is to ensure delivery of safe, consistent, appropriate care; both written and clinical testing may be used; staff are tested on both generic and specialty-specific skills. “
  - Farlex Medical Dictionary
Why do we think it is necessary?

- Many times initial training occurs during a time of stress for caregivers
- Inconsistent training provided by DME companies
- Sometimes there is a long period of time between initial training and actual use of the equipment in the home
- Normal clinic follow up on equipment consists only of verbal reviews (in our clinic)

Why do we think it is necessary?

- Recent complex care listserv topic: Shortage of home nursing due to several factors. (from several different states in the U.S.)
  - Reimbursement
  - Training
  - Regulations for hours allotted
  - Lack of adaptive equipment in the home

Current literature

  - Describe the learning process of carers who manage equipment and procedures at home
  - Limited attention paid to the learning process, few articles
  - Interviews with 26 carers and 15 health professionals
  - “Further thought should be given to the continuing training and support needs of carers at home”
Current literature

Quotes from carers:
- “I ended up teaching our GP, going through the procedure and showing him how it worked”
- “I am physically buggered... I got really depressed”
- “It’s closed a lot of our world socially”
- “when you go home suddenly you’re by yourself”
- “I guess as she changes, we have to change techniques, so I’m forever trying to problem-solve”

Current literature

14th International Conference on Home Mechanical Ventilation, 5th European Respiratory Care Association Congress (2015)

- Knowledge and Skills Retention of Caregivers of Children Receiving Long-term Invasive Mechanical Ventilation at Home (Poster 109) Syed, F. et al, Sick Kids Hospital, Toronto, Canada
  - Results suggest need for continuing education for caregivers
- Skilled Caregivers, Individual training Programs and User Interaction Are Necessary Components for Patients With Long-Term Mechanical Ventilation to Experience Good Quality of Life (Poster 95) Kleiven, A. Oslo University Hospital, Markussen, H. University of Bergen
  - Literature review

Current Literature

14th International Conference on Home Mechanical Ventilation, 5th European Respiratory Care Association Congress (2015)

  - Developed education program for initial training. Plan to develop education services or annual knowledge and skills assessment.
Benefits

• Ability to assess actual equipment
• Ability to observe technique
• Improvement of the education process
• Improvement in patient care

Barriers

• Time
• Clinic flow
• Caregiver resistance

Why a pilot project?

• Pilot project to assess the skills validation process
  – Time required
  – Caregiver feedback
  – Appropriate frequency of SV
  – Integration into clinic visit
Who, what, how many?

- 4 skills categories
  - Ventilator
  - Manual I/E (cough assist)
  - HFCWO (vest)
  - Respiratory Medications and delivery devices

Who, what, how many?

- 16 participants
  - Ranging in years of experience from 17 to less than three months
- Average time required for skills validation
  - Ventilator: 40mins
  - HFCWO: 30 mins
  - Manual I/E: 20 mins
  - Medications: 15 mins

Process

- Notified participants by mail and follow up phone call before clinic appt.
- Completion pre-survey at time of registration
- Performed the skills validation either after normal clinic visit or during clinic “wait time”
- Completion of post-survey
What did we find

- 88% of participants agreed that they would like to have skills validation exercises performed for all of their home equipment
- 56% of participants reported an increase in confidence in using their equipment
- 75% of participants did not meet criteria in at least one area of their skills validation
What did we find?

- settings not optimal (I/E), no chest rise
- incorrect spacer and technique
- incorrect settings (vest)
- incorrect set up of tubing and mask (grey tape)
- did not know settings (vent)
- alarm causes and troubleshooting (vent)
- incorrect cleaning techniques

Pre vs Post Survey Results

Conclusions

- Skills validation improves caregivers knowledge and confidence
- Skills validation is an activity that can be performed during regular clinic visits without disrupting clinic flow
- Caregivers view skills validation as a beneficial exercise