Dementia, Feeding Tubes and Goals of Care an A3 Project

Collaboration Between Palliative Care and Speech Therapy

Good Samaritan Hospital, Advocate Health Care

Advocate Health Care
Tomorrow starts today.℠

The A3 Team

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Abstract:

Introduction: *The inpatient interdisciplinary Palliative Care team identified the issue of feeding tube placement in Advanced Dementia patients as a cause for ethical distress in families as well as the healthcare team.* A New England Journal of Medicine editorial from 2000 concluded that PEG tubes "are generally ineffective in prolonging life, preventing aspiration, or providing adequate nourishment in patients with advanced dementia". Similar declarations have been made in recent published literature. *The Advocate Palliative Care Team in collaboration with Speech Therapy Team initiated an A-3 quality assurance study from this data.*

Method: The targeted population for this study was identified to be patients diagnosed with Advanced Dementia confirmed to have severe dysphagia. The confirmation of severe dysphagia was diagnosed via Videofluoroscopic Swallowing Study (VFSS) and alternative nutrition had been recommended for these patients. The research team retrospectively collected data on the targeted population to determine if a PC consult had been ordered to assist with a GOC discussion. A work flow was then developed to hard wire a process to ensure that the Speech Therapists contacted the Primary Care Physicians (PCP) to obtain an order for PC consult prior to consulting Gastroenterology (GI) in patients confirmed by Videofluoroscopic Swallowing Study (VFSS) to have severe dysphagia and for whom alternative nutrition had been recommended.

Result: Retrospective data showed that 14% of the STs were already contacting the PCP prior to the process being hard wired. The study target goal for ST contacting the PCP to obtain the PC order was set at 30%. The study outcome exceeded the goal at 92%. The second metric measured the percentage of PC consults ordered for the targeted population. Retrospective data indicated 42% of consults were ordered prior to intervention. Target result was set at 85% post-implementation of the new work flow, the result was 100% of identified patient received a PC consult.

Conclusion: This study discovered a statistically significant positive consequence of the PC consult GOC discussion resulting in the following; Prior to the intervention, only 14% of the targeted population resulted in the STs contacting the PCP for PC consult with 100% of the targeted population having had short term and/or long term feeding tubes placed. Post implementation 100% of the targeted population had PC consult GOC discussions with only 14% having PEG tubes placed and 85% choosing not to have short or long term feeding tubes placed. The data validated the daily practice of the Palliative Care team's experiences. Other positive observations noted post implementation were: Palliative Care Program began postponing consulting GI Specialist. GI Specialists delayed their consultation with patient's decision Maker until after the goals of care discussion had occurred with the Palliative Care team. Families reported feeling increased support with consistent messages from healthcare providers. Reduced moral distress was noted in families/substitute decision makers and healthcare providers. Speech Therapists reported feeling empowered to start discussions with families regarding alternative strategies and obtaining palliative care consults from primary physicians.

References:

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BOX 1: Reason for Action

Approximately 50% patients with advanced dementia have feeding tubes placed without burden vs. benefit discussion.

Trigger	→	Done
Patients with dementia, confirmed severe dysphagia, recommend alternative sources of nutrition		Burden vs. benefit of feeding tube discussion occurs with Designated Decision Maker

In Scope:
- Inpatient with diagnosis of dementia
- Confirmed severe dysphagia

Out of Scope:
- Outpatient
- Inpatient without diagnosis of dementia

BOX 2: Initial State

- Treat individual disease rather than whole person
- Create false hopes of recovery
- Designated decision maker/family frustration, physical, emotional, spiritual, financial
- Staff distress due to lack of patient-centered discussion of burden vs. benefit

Metric	Initial (N=7)	Target	Confirmed
%of patients for whom speech contacted attending MD for palliative care consult	14%		
% patients with dementia, confirmed severe dysphagia, recommended alternative nutrition had palliative care consult	42%		

BOX 3: Target State

- Designated Decision Maker engaged in process of decision making
- Fewer feeding tubes placed without medical evidence-based support
- Reduce staff distress when discussion of burden vs. benefit occurs
- Improve quality of life for patient and family

Metric	Initial (N=7)	Target	Confirmed
% speech contacted attending MD for palliative care consult	14%	30%	
% patients with dementia, confirmed severe dysphagia, recommended alterative nutrition had palliative care consult	43%	85%	

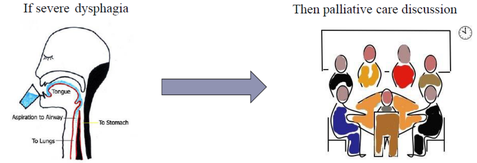
BOX 4: GAP ANALYSIS

- Speech Therapists confirm severe dysphagia and recommend alternative nutrition, with no trigger for burden vs. benefit discussion
- Continued aggressive treatment without considering patient-centered care or goals of care
- Burden vs. benefit discussion difficult for physician especially doctors with attachment to patients
- Designated Decision Maker/family many times defer to doctor's recommendation without receiving informed consent
- GI Physicians assume burden vs. benefit discussion occurred prior to them being consulted.

BOX 5: Solution Approach

If we….	Then we…
If confirmed severe dysphagia, recommended alternative nutrition triggered palliative consult	Then discussion of burden vs. benefit considering patient-centered care would happen
If burden vs. benefit discussion provided current best practice recommendations for patients with dementia	Then designated decision maker family would be able to make informed decisions with better understanding of disease progression and respecting patient wishes

If severe dysphagia → Then palliative care discussion



BOX 6: Rapid Experiments

-Speech Therapist
- calls the Primary MD prior to feeding tube placement for palliative care consult
  OR
- calls Palliative Care if they were involved in patient's care prior to severe dysphagia being confirmed

-Flow chart process improves Designated Decision Maker receiving consistent information

-Speech Rx, MD, & Palliative Care consistency reduces stress for Designated Decision Maker

-Consistent message to Designated Decision Maker

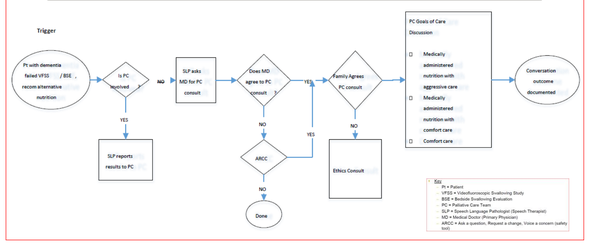
-Reduce Designated Decision Maker false hopes

Flow | Standard Work | Transparency | Tight Connections

-Speech Therapy and Palliative Care communicate and work together seamlessly

-Changed workflow for Speech Therapy and Palliative Care

Flowchart



BOX 7: Completion Plan

Completion:

What	Who	When
Complete Visio Flow Chart	Anna Lee	Done
Create/continue data collection to monitor outcomes	Teri, Naomi	Done
Explore hard stop for no referral to GI for feeding tube prior to palliative care consult	Angie, Teri	Done

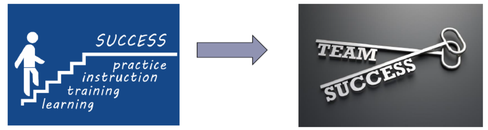
Communication/Training:

Continue to train & evaluate workflow for new Speech/Palliative Care team members	Speech Palliative Care	Ongoing
Increase awareness and engage physicians and associates in the process	Speech Palliative Care	Ongoing
Train Care Managers & Social Workers in workflow and benefits	Speech Palliative Care	June

BOX 8: Confirmed State

RIE Metric:

Metric	Initial (N=7)	Target	Confirmed (N=14)
% of patients for whom speech contacted primary physician for palliative care consult	14%	30%	92%
% patient with dementia, confirmed severe dysphagia with recommendation for alterative nutrition had palliative consult	43%	85%	100%



Results

- Retrospective Review (14 charts)
  - 7 patients met criteria for dementia with confirmed severe dysphagia and recommendation for alternate nutrition
    - 14% of the time Speech Therapist contacted the Primary Physician for a palliative care consult
    - 3 of 7 (43%) patients had a palliative care consults
    - 7 of 7 (100%) patients had short or long term feeding tube inserted
    - 7 of 7 (100%) patients discharged to SNF or Rehab
- Study Outcome
  - 14 patients met criteria for dementia with confirmed severe dysphagia and recommendation for alternate nutrition
    - 92% of the time Speech Therapist contacted the Primary Physician for a palliative care consult
    - 14 of 14 (100%) patients had a Palliative Consults
    - 2 of 14 (14%) patients had a feeding tube inserted
    - 12 of 14 (85%) patients did not have a feeding tube inserted
    - 10 of 14 (71%) patients discharged to hospice/palliative
    - 4 of 14 (29%) patients discharged to SNF or Rehab

BOX 9: Insights and Reflections

Our Insights from this Process (aha):
- Passionate stakeholders
- Process changed patient outcomes
- Associates thinking changed
- Data collection can be challenging
- Secondary affect - consistent message to designated decision maker/family

How is the New Process more Respectful of People?
- Align patient's values with goals of care
- Standard work process is repeatable and sustainable
- Respect for patient's whole person, patient centered care, family supported
- Secondary gain-decrease insertion of non-medically indicated feeding tubes in patients with advanced dementia

Challenges to the Change Process:
- Sustaining process of change
- Nuances of data collection
- Engaging physicians in awareness and outcomes

Actions Required to Sustain or Build on this Change?
- Ongoing evaluation/updating process
- Increase Palliative Care staff to address volumes of referrals
- Increase basic palliative care knowledge for all clinicians on burden vs benefit discussions