

Managing Complex Risk in Ethical Dysphagia Management

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Plan for seminar

- Definitions of risk
- Dysphagia risk management frameworks
- Risk, ethics and evidence based practice
- Embracing a model of risk acceptance
- Case presentations and discussions
- Questions

What is risk?

Definitions

- Hazard
- Chance of bad consequences
- Exposure to mischance
- Exposure to chance of injury or loss
- Venture on, take chances on

Definitions

- Chance of something happening that impacts on objectives
- RCSLT - Risk = consequences x likelihood
- ASHA – what is the definition?
- WHO - “a probability of an adverse outcome, or a factor that raises this probability”

**What decisions do we
make in our own life that
involve a level of risk?**

Risky decisions

- Smoking
- Drinking
- Pringles
- Wearing a seatbelt
- Crossing the road

Decision making process

- Potential outcomes?
- Similar decisions in the past?
- What we really want to do?

How do we come to clinical decisions?

RCSLT

- Principles embedded in law
- Clinical evidence
- Ethical principles
- Options in relation to risks & benefits
- Decision making with the individual

ASHA

“The objective of risk management is to protect the financial assets of the health care practitioner or institution by eliminating or reducing losses resulting from claims and lawsuits.”

Professional Liability and Risk Management for the Audiology and Speech-Language Pathology Professions (1994)

Professional guidance

- Training & guidance to ensure ‘safety’ (RCSLT)
- “procedures to minimize liability exposure” (ASHA)
- Do these optimize patient care ?

Risk assessment

- Identify risk
- Evaluate risk
- Identify risk remedial action plan
- Monitor effectiveness

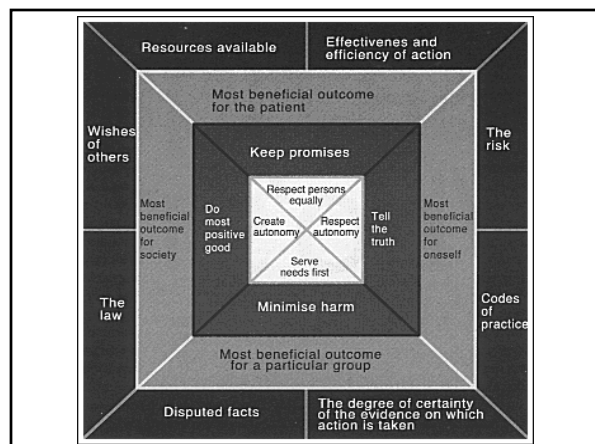
Urgent difficulties	Y/N	Non-urgent difficulties	Y/N
Current pneumonia		Food refusal	
History of pneumonia		Oral stage problems (e.g.) food loss from the mouth	
Current chest infection		Behavioural difficulties at mealtimes	
History of chest infections		Fast eating	
History of serious choking (e.g. hospital/paramedics)		Occasional coughing when eating/drinking	
Coughing at every meal/every drink		Gradual weight loss	
Sudden weight loss		Long mealtimes	
BMI < 15		Difficulty feeding self	
Sudden change in eating/drinking skills		Request for general advice	
Respiratory distress when eating/drinking		Urinary tract infections	

S e v e r I t y	3	MEDIUM	HIGH	HIGH
	2	MEDIUM	MEDIUM	HIGH
	1	LOW	MEDIUM	MEDIUM
		1	2	3

NPSA framework

- Consider all parties
- Nature of problem
- Environment
- Other needs
- Health issues

<http://www.npsa.nhs.uk/health/resources/dysphagia>



Defining evidence based practice?

Evidence Based Practice?

- Anecdotes
- Press cuttings
- Expert opinion
(eminence based practice)
- Cost minimisation
- Desperation

Why must we be ebp SLPs?

- New evidence & patient care
- Clinical performance deteriorates
- Efficacy of intervention?
- Lifelong learning

Evidence Based Practice



Ethics & evidence

- Ethical principles
 - autonomy
 - beneficence
 - nonmaleficence
 - justice
- Code of Practice

What risks are associated with dysphagia?

Dysphagia risks?

- Aspiration
- Temperature spikes
- Wet voice
- Coughing or choking
- Food aversion or refusal
- Lengthy or many meals
- Indications of struggling/pain
- Repeated chest infection (pneumonia)
- Repeated UTIs

Dysphagia risks

- Malnutrition
- Dehydration
- Chest infection
- Repeated UTIs
- Isolation
- Depression

Intervention risks?

- Reduced nutrition
- Reduced hydration
- Reduced social contact
- Reduced overall quality of life
- Reduced patient choice

Balance

- Aspiration ↔ pneumonia
- Thickened liquids ↔ aspiration
- Thickened liquids ↔ dehydration
- Dehydration ↔ health status

Dysphagia management

- Move away from sign & symptom fixing
- Assess factors that cause distress
- Assess dysphagia risks
- Patient preference, control and QOL
- Risks of over riding these?

SLP role in risk

- Inform clients & families objectively
- Reference all areas of ebp
- Support clients & families in their choice
- No SLP 'judgement' about final decision

Competent management uses good quality evidence to inform discussion of risk & treatment options in order to meet professional & ethical standards. The competent SLP will support the client & their family to arrive at the most appropriate individualised treatment approach.

Mike

- 39 years old
- PMLD – CP
- Referred for increased coughing
- Lives at home
- Day center x5 days
- Respite care

Assessment

- ‘Best available evidence’ limited
- Standard department assessment

Discussion

- Aiming at ‘patient preference’ of ebp
- Assessment in different environments
- NPSA - difficulties with social care model

Concerns

- Chesty presentation
- Coughing on all food & drink
- Long & difficult mealtimes
- Low weight
- Limited oral skills
- Behaviours indicating distress

Videofluoroscopy

- Clarify differences with eating & drinking
- Inform future management
- Confirm safe consistencies
- Demonstrate risks to family & carers

Consent

- Mike unable to consent
- Discussed with
 - family
 - care staff
 - care co-ordinator
 - GP
- Agreed in ‘best interests’

Videofluoroscopy results

- Difficulty in controlling liquid
- Difficulty chewing solid food
- Difficulty forming bolus
- Delayed and weak swallow
- Silent aspiration of residue

Action

- Discussion with parents
- Discussion with MDT
- Risk management discussion

Recommendations

- Watching for swallow
- Consistency modification
- Pacing
- Positioning
- Long term monitoring
- Discuss non-oral support

S e v e r i t y	3	MEDIUM	HIGH	HIGH
	2	MEDIUM	MEDIUM	HIGH
	1	LOW	MEDIUM	MEDIUM
		1	2	3
Likelihood				

Benefits of undertaking activity	.Maintaining QOL .Maintaining positive interactions	
Risks associated with undertaking activity	.Development of a chest infection .Choking incident .Weight loss .Reduced QOL	
Action plan to minimize risk	.Dietary modifications .Positioning and support recs .Close MDT monitoring	
	Name & signature	Role/profession
Individuals agreeing and involved with action plan		Parents, SLP, PT, OT, Day centre staff Discussion with Physician

Serious incident

- MDT meeting with parents
- Referral to gastroenterology
- PEG not recommended
- Review for future PEG

Two years on

- Mike continues orally
- Recent chest infections
- Hip permanently dislocated
- Risk management ongoing
- Continue liaison with MDT, family & GP
- Ongoing gastroenterology review

Case discussions

- What are the risks in these cases?
- Who for?
 - patient, family, care staff
 - SLP
 - Organisation

Consider evidence based practice

Stuart is 3 years old. He lives with his mother, who is a single parent. She appears stressed – her appearance is very unkempt, and the house is dirty and untidy.

Stuart has low weight and has had two episodes of pneumonia in the last year. On assessment it is found that his mother feeds him lying down, as this prevents food and liquid escaping from his mouth, but he coughs, without appearing to clear, throughout the meal. Following VFSS he is found to aspirate on all consistencies. His mother says that he enjoys his food. She refuses to consider non-oral feeding.

Helen is 23 years old with PMLD. She relies on others for all activities. She lives at home with her parents and attends a day center. The center referred Helen because she was coughing on food & drink, having panic attacks at meals and refusing food. Helen had pneumonia in the past and is 'chesty'. She weighs 50lbs. On observation she loses a significant amount of food from her mouth and coughs on food and drink. The SLP talked to the parents about Helen's ability to eat, drink & maintain nutrition & hydration, and suggested a VFSS. The mother refused this saying they were managing and a VFSS would panic Helen.

John is 45 years old with a chronic heart condition.

Following a severe cardiac arrest and coma, John regained consciousness and was displaying signs of dysphagia. He was advised to have honey thick drinks and soft diet. On VFSS aspiration was clear on normal drinks and no aspiration with thickened drinks. John was stating clearly that he didn't want thickened drinks, and that he would prefer a PEG.

REFERENCES

- RCSLT. (2006) *Communicating Quality 3* Scotprint
- ASHA. (1994) *Professional Liability and Risk Management for the Audiology and S-LP Professions* ASHA Supplement 12: 25-38
<http://www.nhs.uk/nhs.uk/home.htm>
- WHO. (2002) *The WH Report: Reducing Risks, Promoting Healthy Life*
- Panther K. (2005) *The Frazier Free Water Protocol* ASHA Div 13 Newsletter, 2005
- Pelletier CA, Dhanaraj GE. (2006) *The effect of taste and palatability on lingual swallowing pressure.* *Dysphagia* 21: pp121-128.
- Dorner B et al. (2002). *Position of the American Dietetic Association: liberalized diets for older adults in long-term care.* *Journal of the American Dietetic Association* 102: pp1316-1323.
- Blower, AC. (1997) *Is thirst associated with disability in hospital inpatients?* *Journal of Human Nutrition and Dietetics*, 10, 289-293
- Ekberg O, et al. (2002). *Social and psychological burden of dysphagia: its impact on diagnosis and treatment.* *Dysphagia* 17(2): 139-146
- Westergren, A et al. (2002). *Eating difficulties, assisted eating and nutritional status in elderly (>=65 years) patients in hospital rehabilitation* *International Journal of Nursing Studies* 39(3): 341-351.
- Sackett D et al. (2005) *Evidence-Based Medicine: How to Practice and Teach EBM*. Churchill-Livingstone
- NPSA. (2004) *Understanding the patient safety issues for people with learning disabilities*
- Seedhouse D, Lovett L. (1992) *Practical medical ethics*. John Wiley & Sons Ltd
- Beauchamp T. (1994) *Four principles approach*. In Gillon, R (Ed) *Principles of health care ethics*. John Wiley & Sons Ltd
- ASHA. (2003) *Code of Ethics (revised)*, ASHA Supplement 23, pp13-15

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