

Dysphagia and Quality of Life
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Background

- Dysphagia as a chronic health condition, negatively impacts quality of life (QOL).
- Social and psychological problems are associated.
- Healthcare professionals perceptions the problems often differ from the patient's perceptions
- Careful evaluation by the SLP and the dysphagia team with a joint treatment plan is recommended.
- Providing education about signs of dysphagia and changes in swallowing due to a disease process or treatment for the disease may improve QOL.

Definition of QOL

- A simple definition of QOL is the satisfaction and well-being that an individual experiences on a daily basis .
- QOL is a multidimensional concept, individualized, and highly personal.
- Unique to each person's perception of his or her_situation.
- Swallowing disorders have been shown to have a major impact on global QOL.
- Many activities that add quality to our lives are based around social activities that often include eating.

- Dysphagia creates difficulty eating or health risks.
- Modified diets or ANH may be required.
- Although most people with dysphagia can continue to eat something safely, the fear of eating or the effort involved may greatly reduce the pleasure of the activity.
- Embarrassment may change the places in which a person is willing to eat and limit social activities.
- Slowness and fatigue in eating may impact the effectiveness of eating.
- Diet changes or restrictions may decrease the satisfaction of eating

Families & Dysphagia

- Dysphagia impacts the family system, and members may be reluctant to eat around a person with dysphagia.
- Preparation of special diets requires time and expense.
- Families or caregivers may not believe that changes in eating and feeding are necessary and may not follow-through with medical recommendations.
- Noncompliance often leads to additional health problems such as aspiration pneumonia.
- Alternatively, caregivers may believe diet changes to be necessary when the patient does not, creating conflict.

Quality VS Quantity

- Increasingly, healthcare professionals are emphasizing the importance of quality as well as longevity of life.
- Healthy People 2010 includes a goal that healthcare should not only improve the length of life but also the quality of life.
- Health care professionals need to be mindful of how seriously and profoundly changes in eating can affect an individual.
- Recommendations should not be made lightly or without comprehensive assessment by a skilled dysphagia team.
- All members of the team must be certain that their skills and knowledge are updated with current research, and recommendations should be made based on EBP.
- Multiple areas are impacted by dysphagia – physical, spiritual, emotional, nutritional, and social.

Research Background

- Much of the information about QOL and dysphagia is from studies of individuals with head and neck cancer.
- At least 50% of individuals with H/N cancer experience dysphagia resulting in 10,000 to 20,000 new cases yearly.
- Dysphagia may be caused by either the primary tumor or by the treatment to eliminate the cancer.
- Surgery, radiation, and chemotherapy all may adversely affect eating and swallowing skills, and some individuals will require ANH for at least a period of time.

H/N Cancer

- Swallowing skills change for at least a year after treatment has been completed due to the delayed effects of radiation and especially the fibrotic changes caused by radiation therapy.
- Patients often report trismus or difficulty opening the jaw, stiffness, esophageal strictures, pain, dry mouth and lack of salivation, and loss of taste.
- Gathering accurate QOL data is important for patient education regarding choice of treatment for cancer.
- Organ preservation protocols that limit surgical resections and primarily treat the tumor with chemotherapy and radiation are becoming increasingly more aggressive in dosage and frequency.
- Treatment methods often have equivalent survival rates but differ in permanent side effects.

Measuring QOL

- There are many instruments that have been used to assess QOL in different groups and in studies of individuals with dysphagia.
- Some are very general and related to global health issues. A few are disease-specific such as for types of cancer. Some of these instruments have added subsets of questions to specifically address dysphagia.
- Only a few tools have been designed and validated to specifically address swallowing complaints and the effects of dysphagia on QOL.

SWAL-QOL & SWAL-CARE

- The SWAL-QOL is an outcomes tool for measuring the impact of dysphagia on QOL that has documented validity and reliability.
- The SWAL-QOL assesses the patient's perspectives and is the first tool specific to swallowing disorders.
- The SWAL-QOL is a 44 item tool that assesses 10 QOL concepts, and the SWAL-CARE is a 15 item tool assessing quality of care and patient satisfaction.
- The items on the SWAL-QOL address desire for eating, dysphagia symptom frequency, mental health, social concerns related to swallowing problems, food selection, fear related to eating, and the burden of dysphagia.
- The SWAL-CARE items address recommendations about food, liquid, and dysphagia treatment and satisfaction with treatment.
- These tools are complementary to instrumental dysphagia assessments and screening tools for dysphagia.
- The instruments help to identify patients with oropharyngeal dysphagia and are sensitive to differences in severity level.
- SLPs can use the SWAL-QOL and SWAL-CARE to assess treatment effectiveness and patient satisfaction and improve QOL and care for individuals with dysphagia.

M.D. Anderson Dysphagia Inventory

- The MDADI was the first validated and reliable self-administered questionnaire designed specifically to assess dysphagia and QOL of patients H/N cancer.
- The MDADI can be paired with other QOL measures to obtain different responses and different viewpoints.
- One example is the Short Form Health Survey (SF-36) which is a multi-item scale measuring physical functioning, role functioning, pain, general health, energy level, social functioning, emotional role functioning, and mental health.

Head and Neck Cancer Quality of Life Questionnaire

- This instrument was developed in order to assess disease-specific health-related QOL to evaluate treatment effectiveness for cancer.
- Cancer treatment methods may provide similar survival rates but different side effects, so patients and healthcare providers need this type of information for informed decision-making.
- The HNQOL assesses eating, communication, pain, and emotion.
- Communication items: talking to others, talking on the phone, and problems with clarity and volume of speech.
- Eating items: problems with chewing, dry mouth, taste, swallowing different consistencies, and mouth opening.
- Emotional items: embarrassment about appearance or condition, financial or emotional worries and frustration.
- Pain items: shoulder and neck pain, general physical problems, pain in the mouth, and frequency of pain medication use.

Other Patient-Rated Instruments

- Other instruments available for use with H/N cancer:
- University of Washington Quality of Life (UWQOL) instrument, the Functional Assessment of Cancer Therapy (FACT) instrument, and the European Organization for Research and Treatment of Cancer (EORTC) head and neck instrument.
- All of these instruments have been validated but obtain QOL scores in a composite manner rather than by specific domain items.

Other H/N Cancer Instruments

- The Performance Status Scale for Head and Neck Cancer is a clinician-rated tool with three subscales - eating in public, speech intelligibility, and diet (non-oral to normal). The scales are rated from 0-100 with 100 being normal function, and patients are rated on a continuum from total inability to normal functioning.

Research on Dysphagia & QOL

- Tibbling and Gustafsson (1991) used a mail questionnaire to determine the impact of dysphagia on QOL in a random sample of individuals 59 years and older (N=796).
- Eight percent (N=62) reported symptoms of dysphagia, either esophageal or pharyngeal.
- Half of these individuals reported anxiety at meals, and some stated that this made them want to eat alone.
- Individuals with dysphagia had significantly more instances of chest pain, heartburn and regurgitation, and a history of cardiac symptoms.
- Individuals with esophageal dysphagia preferred to eat alone, while individuals with pharyngeal dysphagia reported that they were too anxious to eat alone.

- Gustafsson and Theorell (1995) interviewed young adults in high school with dysphagia.
- Two questionnaires with 20 questions each and a subsequent telephone interview were used.
- Participants were identified as having dysphagia if they answered affirmatively to a question indicating that food stuck in their chest or their throat when they ate.
- Out of 1,295 students surveyed, 114 reported dysphagia, and 87 completed the study.
- Students were identified as either adapted or maladapted based upon whether dysphagia impacted their lifestyle.
- Those in the maladapted group (N=9) were more likely to have anxiety at meals and were impacted more negatively by the environment and the situation in which they were eating. This group also reported more difficulty coping with swallowing problems and had a higher need for social support.

- Jacobsson et al. (2000) observed 30 individuals with a history of stroke while they ate a meal.

- Observations were made of oral function and feeding skills, and an interview was conducted after the meal.
- Two themes emerged from the interviews – fear of choking and oropharyngeal discomfort.
- Individuals with a history of stroke reported feeling out of control and insecure about physical and social factors and unhappy that they could not enjoy their food.
- Other comments were that they were excessively thirsty; felt discomfort such as nausea or lack of appetite; were ashamed of their appearance related to eating especially if they had leakage of saliva; they were humiliated because they could not eat independently; and they felt hopeless.
- These feelings of fear and discomfort related to eating may impact adequate caloric intake and nutrition and overall psychological health.
- Ekberg et al. (2002) interviewed 360 individuals with complaints of dysphagia in long-term care and clinic settings in Europe.
- Twenty-eight questions were used and covered the areas of background, eating habits, personal feelings and importance, seeking help, and medical status.
- Results indicated that dysphagia created social and psychological consequences and was not well-recognized, diagnosed, or managed.
- Only 39% of individuals believed that dysphagia was treatable, and they reported isolation and loss of self-esteem.
- Many avoided eating with others and felt panicked or anxious at mealtimes. Less than half reported that eating was enjoyable. More than 50% reported that they were eating less than typical, and many were still hungry and thirsty after meals.
- Patients with dysphagia indicated that their psychosocial needs were as critical as their physical needs.

Research on H/N Cancer

- Deleyiannis et al. (1997) studied individuals treated for advanced oropharyngeal cancer with organ preservation (chemoradiation) or surgery before and after treatment.
- Both groups reported a worsening of chewing and swallowing skills from pretreatment levels.
- Over 60% had lost 9kg or greater of body weight at 1 year post-treatment.
- Symptoms of advanced cancer associated with treatment are often reported as worse than symptoms created by the cancer without treatment and decrease QOL.
- Some individuals may prefer a shortened lifespan rather than the decreased QOL caused by treatment methods
- Terrell et al. (1998) completed a long-term QOL survey of veterans through the V.A. with laryngeal cancer treated either with radiation and surgery or organ preservation only (N=46).

- Individuals with chemoradiation had better scores on pain, mental health and emotional areas compared to the surgical group.
- There were no differences between groups on the eating domain although the laryngectomy group did score low on swallowing soft foods/solids and with taste.
- The overall scores on the eating domain for the two groups ranged from 80-85 with 100 being the best score possible.
- Gillespie et al. (2004) also compared QOL results of individuals after H/N cancer treatment with either chemoradiation or surgery with radiation (N=40).
- Individuals in the chemoradiation had significantly better scores on the emotional and functional subscales than did the surgical group.
- Individuals with H/N cancer need to know results of different treatment methods in order to make informed choices about treatment.
- Jones et al. (1992) administered the EORTC with a module added to specifically address H/N symptoms (N=48) to individuals with H/N cancer after surgery.
- Pain, fatigue, physical and psychological symptoms, activity level, overall physical condition, and overall quality of life were included.
- Specific dysphagia items added to the questionnaire addressed weight loss, amount of oral intake, sense of smell and taste, swallowing trouble, and time needed to eat a meal.
- Those individuals with cancer involving craniofacial surgery or cancer of the hypopharyngeal region reported the most swallowing and eating problems and had lower overall quality of life scores than patients after laryngectomy who reported few problems in any area.
- Gillespie et al. (2005) studied individuals with laryngeal cancer treated either with chemoradiation or with surgery/radiation to determine differences in laryngeal penetration and aspiration rates (N=21).
- The Penetration-Aspiration Scale (PAS) was used.
- The PAS measures whether penetration or aspiration occurs, the patient's reaction to this, and the severity level.
- Patients in the organ preservation group had greater airway protection abilities and better QOL related to swallowing than those treated with surgery/radiation.
- Over 50% of patients in both groups required some type of modification to their diet after treatment.
- The group with laryngectomy had higher reported scores of dysphagia symptoms than the chemoradiation group.
- Results indicate that dysphagia is a common consequence of H/N cancer regardless of treatment method.
- There was poor correlation between airway protection scores and QOL.

- Lotemptio et al. (2005) compared QOL outcomes in individuals with laryngeal cancer to determine differences between those treated with chemoradiation and those treated with total laryngectomy (N=49).
- Most reported excellent outcomes and QOL overall regardless of treatment method, but swallowing, chewing, and saliva were reported as significant factors affecting daily QOL.
- The chemoradiation group reported significantly more swallowing problems with 27% reporting that they could not swallow at all.
- Twenty percent of the chemoradiation group also reported that they could not chew at all.
- Total laryngectomy patients reported problems in chewing and swallowing but more frequent QOL issues related to speech and shoulder function.
- The authors noted that since people treated with organ preservation methods were still able to speak, they may not have had the benefit of speech and swallowing therapy which could improve their swallowing outcomes.
- El-Deiry et al (2005) also compared QOL in patients with chemoradiation versus surgery 12 months after treatment.
- The two groups reported similar results in QOL.
- The HNCI was used and is a 30 item validated survey that measures specific outcomes in speech, eating, aesthetics, and social disruption. Scores range from 0-100 with 100 being the highest rating.
- Mean scores on the eating domain were around 40; means for the speech domain were around 60, and social disruption about 70.
- In advanced H/N cancer, 12 months post-treatment, QOL is still adversely affected.
- Results of a majority of the research in H/N cancer indicates that regardless of method of treatment, side effects occur related to eating, QOL is affected by swallowing and chewing problems, and the effects vary in severity and perceived-importance based upon the type of cancer treatment.

Esophageal Dysphagia Research

- Gustafsson and Tibbling (1991) interviewed 19 patients with esophageal dysphagia with etiologies including achalasia, hiatal hernia, and esophageal strictures.
- All individuals rated their dysphagia as a handicap.
- Specific problems were being unsatisfied after eating, having difficulty eating, being insecure or fearful when eating, feeling out of control when eating, being reluctant to eat with other people, and lack of pleasure with eating due to required modifications such as drinking extra water.
- Other activities reported as restricted because of dysphagia were work, including being forced to take early retirement due to health problems; inability to exercise; restrictions in leisure activities such as social activities or traveling.

- All patients reported decreased self-esteem due to their dysphagia. Some reported feeling insecure, guilty, or ashamed.
- Most felt that they had not had adequate acknowledgement and understanding of their problem from their physician at their initial consultation.

Patient Suggestions

- King et al. (1985) interviewed patients receiving radiation treatment for varying types of cancer weekly during treatment and monthly for 3 months after treatment was completed.
- 50% of patients receiving radiation to the H/N reported swallowing problems about 50% of the time throughout treatment, and severity was rated as moderate.
- Patients reported that it was helpful when nursing staff gave them anticipatory knowledge of symptoms that could be caused by radiation such as swallowing problems.
- Nursing suggestions to address these symptoms were helpful to them such as eating frequent small meals to avoid weight loss.
- Healthcare professionals should be informed about the likelihood of dysphagia with particular disease processes and treatments and be able to make basic recommendations for treatment and referrals.
- Loizou et al.(1992) found that among individuals with inoperable esophageal cancer (N=22) healthier patients complained more about swallowing problems decreasing QOL than individuals in later stages of cancer.
- As dysphagia increased, QOL scores decreased.
- Patients who had improvement of dysphagia symptoms through palliative treatment of the cancer exhibited improved scores on QOL measures.
- The authors concluded that treating dysphagia symptoms in this group was important for improving QOL and should be a component of palliative care.

Diet Modifications & QOL

- Individuals may be noncompliant with recommendations that change their food and drink.
- Many complaints about diet modifications are valid.
- Many people do not like water when thickener is added. They complain about the "mouth feel."
- Macqueen et al₂ found that 75% of patients did not like thickened liquids, and this distaste could lead to decreased fluid intake and dehydration.
- Garcia et al₂ found that nearly half of patients surveyed had a strong dislike for honey or pudding-thick liquids.
- Greater compliance can be achieved when the thickening is recommended short-term and for a small increase in viscosity such as nectar.

Pureed Food

- Many patients refuse pureed foods and may describe it as baby food.
- 15-20% of individuals in long-term care receive this type of diet.

- Visually-appealing food is more acceptable and will improve oral intake. Cassens et al. demonstrated a 15% increase in oral intake in residents when they were given pureed foods in a three-dimensional form.
- Mohide et al. (1992) elicited QOL data from healthcare providers and patients with laryngectomy (N=20 in each group) to compare what each group ranked as most important.
- 17/20 of the health professionals were either physicians or nurses.
- Healthcare professionals ranked communication and self-image as most important while patients ranked physical changes after surgery, such as issues involved with having a stoma, and negative social changes as most important.
- 3/5 of the most important criteria for QOL were chosen by both groups but not in a similar order.
- It could be inferred that healthcare professionals' views of important QOL factors could differ from the patient's
- Consumers often report dissatisfaction with the quality and effectiveness of interactions with healthcare providers, especially when seeking diagnosis.
- Individuals with esophageal dysphagia completed an interview and questionnaire to determine their experiences after their initial consultation with a physician for dysphagia (N=39).
- 64% felt their problem was not recognized, acknowledged, accepted, or assessed by a physician who was knowledgeable about dysphagia
- Individuals with dysphagia expressed fear of cancer, and this fear was unresolved after the appointment with their physician.
- Healthcare professionals overestimate levels of patient compliance with treatment recommendations.
- This suggests that professionals and patients may have differing views of most important aspects of care.
- Patients frequently feel that dysphagia symptoms are not recognized or acknowledged and that they are not given a clear diagnosis by physicians.
- Healthcare professionals may view the physical manifestations of dysphagia as most important, while patients often put a higher priority on the psychosocial ramifications.
- To provide optimal care, both areas must be addressed and prioritized through joint discussion between patient and healthcare provider.

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