

CONTENT EXPERTISE

Feeding Tube Use and Employment

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Keywords: employment, return to work (RTW), head and neck cancer (HN), feeding tube, survivorship

<https://doi.org/10.70385/001c.132439>

The Rehabilitation Professional

Vol. 33, Issue 1, 2025

This study is concerned with the possible barriers to employment for a person who is using a feeding tube for nourishment. This narrative review will illuminate the information concerning the use of a feeding tube and returning to work after medical treatment for head and neck cancer. According to White and McBurney (2013), a narrative review involves a person telling a story first hand. The reader will hear directly from the participant in the narrative. Green et al. (2006) noted that narrative reviews written with a specific opinion can be considered commentaries, and the bias of the writer is apparent. During January 2024 to January 2025, this writer explored various databases (CINAHL, MEDLINE, Alt health watch, Health Source-Nursing Academic Edition, Health finder, PubMed) and yet found a paucity of information concerning people using feeding tubes and employment. Particular interest was placed on information concerning those recovering from head and neck cancer treatments, using a feeding tube, and returning to work. It seems possible that the lack of information is because returning to work has not yet been well defined. It also seems that the lack of information about people returning to work after cancer treatment is because most people are considered “fully recovered” with the feeding tube being removed before returning to work.

Introduction

Yu et al. (2022) noted that Head and Neck (HN) cancer is the sixth most common type of cancer worldwide. HN cancers include tumors in one's nasopharynx track, oral cavity, larynx, sinuses, and pharynx. The median age at diagnosis is 66 years old. Treatments include surgery, radiotherapy, and chemotherapy. Bossola, et al. (2022) and Yu et al. (2022) noted that adverse side effects include swallowing, malnourishment, xerostomia (dry mouth), loss of taste, and impeded speech. Disfigurement from treatment is also a possible side effect of treatment. Barbon et al. (2022) noted that oral intake ability by the patient is associated with continued swallowing exercises via speech therapy during radiation treatment. Hazzard et al. (2019) studied those who experienced swallowing difficulties and chose to have a percutaneous endoscopic gastrostomy (PEG), or a feeding tube, surgically inserted. The experiences of those who chose the use of a PEG included fear and reluctance, physical discomfort, restrictions to social life and daily living, yet gradual acceptance. Yu, et al. (2022) noted that those with HN cancer may have more difficulty to return to work. Returning to work (RTW)

creates a sense of normalcy for one's life. Some people need to return to work to secure an income and insurance. This writer was diagnosed at age 64. Treatments included concomitant radiation and chemotherapy over 5 months, and the use of a PEG for 11 months total, 7 months while employed.

Domb et al. (2022) and Bains et al. (2011) both highlighted the gap in educating the patient about the side effects of chemotherapy and radiation. Domb et al. referred to "patient care" as fragmented. The misunderstanding leads to confusion. To highlight the lack of information for patients, this writer was simply handed a notebook by a nurse at the onset of chemotherapy and radiation. Emotions experienced by this writer during this period of time included frustration, confusion, anger, but also determination.

Eze et al. (2006) and Bossola et al. (2022) studied the complications people encountered when using a (PEG) while undergoing treatment for head and neck cancer. Eze et al. noted that traditionally HN patients used a nasogastric tube. However in 1980, (PEG) was first described by Gauderer. The PEG became the instrument used for long-term use. Complications noted by Eze et al. and Bossola et al. were the same complications experienced by this writer: leakage, blockage, and abscess formation. However, as noted by Eze et al., gastrostomy tubes have advantages over nasogastric tubes: patient comfort, improved function for nutrition, and much better cosmetic outcome- because the PEG is hidden behind the patient's shirt.

Ackerstaff et al. (2002), from the Netherlands, studied the quality of life of 50 HN cancer patients, some of whom used a PEG. Self-administered was the Dutch-Flemish translation of the Functional Assessment of Cancer Therapy-Head and Neck questionnaire (FACT-HN). The FACT-HN has 11 specific questions concerning HN cancers. Also self-administered was the University of Washington (UW) questionnaire. The UW consists of categories concerning pain, disfigurement, employment, eating, taste, saliva and speech. At 12 months, 21 patients returned to a normal diet, 5 patients still needed a PEG. Of 18 people who were employed at diagnosis, 10 were able to return to work within 12 months. Again, what is considered "return to work" is not specified, nor is the use or barriers of a feeding tube described.

Bozzetti et al. (2021) used a 19 item questionnaire in Europe to study the use of naso-enteral tube or a PEG with 220 HN patients. Patients from Italy, Spain, and Sweden contributed to the study. For short-term use, the naso-enteral tube was preferred, but the PEG was used if external feeding was needed for more than a month. Returning to work was not evaluated.

Wells et al. (2015) used the Patient Concerns Inventory to research the unmet needs of HN cancer survivors in England. The most common concerns and unmet needs included oral and eating problems and fear of reoccurrence. Being out of work, living alone, and having a feeding tube fitted were other unmet needs also expressed by the patients. With this study, employment was a concern but not explored further. There was no mention of difficulties experienced such as timing of feeding sessions and privacy.

McQuestion et al. (2011) noted that people receiving radiation and chemotherapy for head and neck (HN) cancers experience common side effects. First, people experience an emotional strain of being diagnosed. Then during and after treatment, people experience precarious weight loss and complex nutritional issues. McQuestion et al. highlighted the lack of research conducted on the challenges of eating and the meaning of food for HN cancer patients.

McQuestion et al. stated that the impact to one's eating can and often does last into survivorship. For nutrition, this writer fed herself via PEG 2x a day. Plus, this writer was able to drink protein drinks to receive appropriate nutrition. It was not until 4 months after the last radiation treatment that this writer was able to learn from a nutritionist exactly what nutritional strategies would be best for recovery. As McQuestion et al. emphasized, little attention has been paid to the patient's perspective about the meaning of food and eating as the patient develops a new "normal" for survivorship.

Lize et al. (2020) presented the concept of Psycho-Oncology to explore the psychosocial dilemmas of not being able to eat during and after treatment. Lize et al. included caregivers as well as patients in their study. Themes that emerged from this study included the caregivers having a great sense of responsibility for their patient to eat. Other themes included situations that the writer experienced such as feelings of disappointment that though medical recommendations were being followed, one's weight continued to drop. Lize et al. noted that beside the alternatives to eating, patients also developed food aversions, taste alternations; it becomes painful to chew and swallow due to radiation damage and burns. This writer lost 35 lbs. during treatment. Food aversions developed toward chocolate. Radiation treatments had caused scar tissue in the throat and on the skin of the neck. Lize et al. noted that in the field of Psychosocial Oncology there has been an increase in the knowledge of the emotions associated with eating difficulties, but still the area involving HN cancer lags behind. Lize et al. noted results indicated that both patient and caregiver experience strong emotions of anger and anxiety pertaining to the reduced ability to eat. This writer's caregivers monitored the intake of a variety of soft foods.

Greco et al. (2020) noted that patients with HN cancers experience acute and chronic toxicities, including dysphagia (swallowing), xerostomia (dry mouth), fibrosis, and neuropathies that can exacerbate dysphagia. Greco et al. focused on a 5 year cohort of patients with HN cancers. Of 977 participants, those with nasopharynx cancer used their PEG 119 days, hypopharynx was the highest use days at 126. This writer continues to experience dry mouth. Dental hygiene care is needed to protect the health of gums and teeth. Concerning speech, Logan and Landera (2021) surveyed their colleagues, fellow speech pathologists, concerning treatments for those patients using a PEG. Results indicated a variation of treatments used with no clear decision made.

Methods

During 2024 January to January 2025, databases CINAHL, MEDLINE, Alt health watch, Health Source-Nursing Academic Edition, Health finder, PubMed, were explored using the key words of employment, return to work (RTW), head and neck cancer (HN), feeding tube (PEG), and survivorship. As a survivor and currently gainfully employed full time, this writer's narrative review will illuminate the information concerning the use of a feeding tube (PEG) and returning to work (RTW) after medical treatment for HN cancer. Guidelines from White and McBurney (2013) and Green et al. (2006) will be followed so that the writer's voice and experience can be shared and contributed to the field.

Discussion

Miller (2020) noted the lack of evidence worldwide pertaining to HN cancer and RTW. Even though younger people are being diagnosed with cancer, it's difficult to make conclusions regarding employment. Lamore et al. (2019) noted that there were 15.5 million cancer survivors in the USA, and many of these survivors were employed. Unfortunately, "return to work" (RTW) after a severe illness has yet to be defined in the academic/scientific literature. One may assume that RTW is when people "restore their former lifestyle." Guo et al. (2021) suggested a definition including the resumption of paid part-time or full-time work for a number of committed hours per week.

Zhang et al. (2023) suggested that helping survivors return to society after treatment is both a medical and social issue. As the ultimate goal of rehabilitation, RTW can be defined as a way to maintain social interactions, self-identity and normalcy, as well as mitigating against financial burden and improving quality of life and survival rate. Zhang et al. emphasized the lack of evidence worldwide of the RTW for HN cancer.

Chang et al. (2023) developed a quasi-experimental study to evaluate the effects of a RTW program/intervention for HN cancer patients. Both the experimental group and control group were assessed at 9, 12 and 15 months. The results indicated that those who received the intervention had higher self-perceived health status and psychosocial functioning. The RTW intervention consisted of vocational counseling, assistance for transitioning back to work, patient support-groups, and a handbook for guidance. The experimental group had access to a "research nurse" and received face to face educational sessions. The "research nurse" also provided telephone sessions. This writer noticed that "research nurse" was not defined nor did the study acknowledge HN survivors with a PEG. Replicating this study for other HN survivors would seem difficult. It comes to mind that a Rehabilitation Counselor could take the place of a "research nurse" and a more thorough intervention could occur.

Ehrsson, et al. (2023) developed a study to predict those HN cancer survivors who would RTW. It was noted that RTW can have important benefits for the survivor's well-being. A primary hindrance to RTW included the stage of the cancer (III-IV). The study indicated that RTW was facilitated by having an early stage of cancer, a white-collar job, and living within a relationship. This study did not mention PEG or swallowing/eating issues. This writer had stage III cancer, detected after one year, had a white-collar job, and living within positive relationships.

The U.S. Equal Employment Opportunity Commission (EEOC) enforces the employment provisions of the ADA, now the ADAAA of 2008. This document clarifies that responses to questions or disclosures of cancer are voluntary; that reasonable accommodations are made; safety concerns are noted; and the employee is not harassed. People with cancer still experience barrier to equal job opportunities. As a result of the updated ADAAA, people who have cancer or those in remission should be found to have a disability within the meaning of the first part of the ADAAA definition of disability because they are substantially limited in the major life activity of normal cell growth, or if in remission, the cancer returned. Individuals with a history of cancer would be covered under the second part of the definition of disability because they have a record of impairment that substantially limited a major life activity in the past. Individuals are covered under the third part of the definition of disability if an employer refused to hire or dismissed the individual because the employer believes the person has cancer. Such provision should establish more specific research of HN cancer patients returning to work.

Conclusion

The use of a PEG and the barriers it creates is not mentioned often, even within the HN cancer research. However, the 2021 Bristol Myers Squibb "Back to Work Guide for Head and Neck Cancer Patients did mention the use of a PEG. A survivor was willing to discuss returning to work with a PEG. The survivor carefully planned her at work meals and prioritized what nutrition she needed. The survivor emphasized being prepared to avoid an embarrassing situation with her PEG. From this writer and survivor's view, the research and guidance books lack specific and blunt descriptions of what may be considered an embarrassing situation with a PEG.

From this review of literature, research is now gradually focusing on HN cancers-primarily because younger people are being effected- but a focus on PEG use and RTW is still lacking. Using a PEG or other feeding tube device can be found in the literature, but the specifics of use, maintenance, and updates for the device is lacking. As a survivor of HN cancer, this writer experienced a variety of instructions concerning the use of the PEG. For example, "flushing" the tube required water to "flush" debris from the tube. The water would go directly into the stomach. I received instructions normed on a 6 foot, 205 lbs. male patient. As a 5 foot, 80 lbs. female patient, I had to modify and create my own flushing intervention. Defining "return

to work” may be best defined individually by each survivor who does return to employment. This writer desired to return to work full time for financial and insurance benefits as well as an enjoyment. This writer returned to work after learning how to manage the PEG and receiving excellent guidance from a nutritionist. More research needs to focus on RTW, especially as younger people experience head and neck cancer. The Rehabilitation Professional can be utilized to support one’s efforts to maintain or obtain employment.

Submitted: March 01, 2025 CDT. Accepted: March 01, 2025 CDT. Published: March 15, 2025 CDT.



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