

# Dysphagia training after head and neck cancer fails to follow legislation and national recommendations

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## ABSTRACT

**INTRODUCTION:** Dysphagia is a known sequela after head and neck cancer (HNC) and causes malnutrition, aspiration pneumonia and a reduced quality of life. Due to improved survival rates, the number of patients with sequelae is increasing. Evidence on the ideal HNC-specific rehabilitation of dysphagia is lacking, but several studies indicate that early initiation is crucial. The aim of this study was to map the existing dysphagia rehabilitation programmes for HNC patients in Denmark.

**METHODS:** Occupational therapists (OTs), oncologists and surgeons from five hospitals participated in a nationwide questionnaire-based survey, along with OTs from 39 municipal health centres.

**RESULTS:** HNC patients rarely receive preventive occupational therapy before treatment, and hospital-based OTs mainly attend to HNC patients undergoing surgery. Far from all oncology and surgical departments complete the required rehabilitation plans upon discharge which leaves many patients untreated. There are vast differences between the municipalities' rehabilitation programmes and between the expertise employed in municipalities and hospitals.

**CONCLUSION:** Existing HNC rehabilitation does not meet official Danish guidelines. Only a fraction of HNC patients are offered rehabilitation and often long after completing treatment. Municipal rehabilitation services vary considerably in terms of type, duration, intensity and expertise. Dysphagia-related rehabilitation requires an improved monitoring, possibly with an increase in the uptake of centralised dysphagia rehabilitation.

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Approximately half of all head and neck cancer (HNC) patients experience severe dysphagia as a late effect of the tumour itself and/or due to the side effects of their cancer treatment. Dysphagia can cause malnutrition, aspiration and pneumonia, and it can affect the patient's quality of life when he or she cannot eat and participate in daily activities around a meal with other people [1-4].

In Denmark, the therapeutic assessment and rehabilitation of dysphagia are tasks primarily performed by

occupational therapist (OT), although dysphagia has, so far, primarily been managed within neurology [5].

Every year, approximately 1,400 new cases of HNC are diagnosed in Denmark [6]. The incidence is steadily increasing and improved treatment regimens lead to higher survival rates. The prevalence is currently 14,000 [7, 8]. The 5-year survival point reaches an average of 60%, but the treatment causes extensive sequelae, including dysphagia [6, 8, 9]. Nevertheless, the attention directed towards rehabilitation to this patient group is limited.

According to Section 84 of the Danish Health Act (Sundhedsloven), all patients residing in Denmark shall have their rehabilitation need assessed by a health-care worker upon discharge from the hospital. If needs are identified, a rehabilitation plan (*genoptræningsplan* = GOP) is prepared in cooperation with the patient. The "Pathways for Head and Neck Cancer" (*Pakkeforløb for hoved og halskræft*) describes the importance of early intervention, and recommends that patients are referred for specialised perioperative rehabilitation as well as post-operative swallowing rehabilitation [6]. In Denmark, "specialised rehabilitation" refers to hospital-based rehabilitation implemented in close collaboration with physicians. Hence, "specialised rehabilitation" must be distinguished from "rehabilitation at a specialised level", which is implemented by the municipality and handled by therapists with specialised competencies within their subject area [10].

The purpose of this questionnaire survey was to map the rehabilitation currently provided to HNC patients and to explore whether it meets the official recommendations and legislation, and if it is in line with current evidence. Ultimately, the aim is to question the present rehabilitation strategy in the field.

## METHODS

A total of 39 rehabilitation centres (RCs) distributed in 33 of the country's 98 municipalities participated in the survey along with the five hospitals (from a total of 53 public hospitals) responsible for HNC treatment in Denmark (Rigshospitalet, Herlev, Aalborg, Aarhus and Odense hospitals). To ensure a geographically and socio-economically representative sample, we included the

## ORIGINAL ARTICLE

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two municipalities with the lowest personal income level (PIL), the two with the highest PIL and the two municipalities closest to the average PIL in each of the five regions. Regardless of PIL, all of the regions' largest municipalities were included. Those with fewer than 20,000 inhabitants were excluded. The survey was carried out in January 2014, and it included only those RCs that would receive patients with dysphagia and HNC.

An invitation to participate in the survey was sent to each of the relevant hospital departments stating that the survey should be completed by a doctor responsible for HNC oncology or surgery, respectively. Municipalities and clinics for occupational therapy at the five hospitals were contacted directly in order to identify OTs responsible for HNC rehabilitation within their hospital or municipality. Questionnaires were then sent specifically to those OTs. The accompanying letter specified that only one questionnaire should be completed per clinic or RC although several respondents were allowed to answer the questionnaire together on behalf of their workplace.

This process yielded a total of 53 questionnaires (39 RC-based OTs; five hospital-based OTs; nine oncologists and four oto-rhino-laryngologists. In general for both RCs and hospitals, 1-3 OTs undertook the task of HNC rehabilitation per workplace. It is not known on behalf of how many oncologists and surgeons the responding doctors gave their answers in their respective departments.

The questionnaires were designed to specifically target the above-mentioned groups. Hence the survey was based on three different questionnaires – one for municipality OTs, one for hospital OTs, one for doctors – which included ten, ten and six questions, respectively, covering areas such as frequency of HNC patients with dysphagia; indication for rehabilitation and referrals hereto; type, duration and intensity of therapy; and professional skills, qualifications and knowledge.

Data were analysed in SPSS and Excel. The survey was complemented with statistical summaries from the Danish Cancer Society's monitoring of GOPs for cancer patients in the 2007-2012 period [11].

*Trial registration:* not relevant.

## RESULTS

The overall response rate was 89%. Eight of nine (89%) doctors (five oncologists & 3 oto-rhino-laryngologists), five of five (100%) OTs in hospitals and 34 of 39 (88%) municipality-based OTs responded. In all, 31 of 33 (94%) of the approached municipalities were represented in the survey by one or more RC. All responding doctors were either medical consultants or chief consultants.

### Referrals and rehabilitation plans

The survey shows that in two of the five hospitals, OTs did not see HNC patients with sequelae until several years after end-of-treatment. Among doctors there are wide differences in the perception of how many HNC patients have dysphagia, with estimates ranging from 15-100% prior to treatment and from 25-90% after treatment. Responding doctors estimated that a mean of 10% of HNC patients are referred to occupational therapy directly from their department. These estimates range from 0% to 40% (95% confidence interval: -0.48-20.48) and that those referrals are always made after the curative treatment. Half of the doctors ( $n = 4$ ) say that in certain cases they refer patients to lymphoedema therapy and/or to specialised rehabilitation by OT at the hospital in the first couple of months after treatment.

### The rehabilitation and the therapist's competencies

To get an indication of the therapeutic competencies and the rehabilitation provided to HNC patients, we asked specifically about four exercises (Shaker, Effortful Swallow, Mendelsohn and the Masako manoeuvre) because international studies have shown that these exercises are effective in the rehabilitation of HNC patients with dysphagia [9, 12]. Generally, the exercises are well known at the five hospitals, whereas a significant proportion of the municipality-based OTs have limited knowledge of the exercises (Figure 1).

12% of the RCs and 20% of the hospitals have OTs with specific cancer rehabilitation training. All hospitals and a third of RCs have OTs with experience specific to HNC rehabilitation (Figure 2). One municipality indicated that social- and health service (SoSu) assistants perform the swallowing therapy rather than a competent therapist. The majority of RCs (76%) annually receive  $\leq 5$  HNC-patients, and 24% have never received patients with HNC.

A head and neck cancer patient learns to correctly perform the Shaker exercise with the assistance from an occupational therapist.



## DISCUSSION

A total of 80% of HNC patients experience acute dysphagia from the curative treatment, 46% have dysphagia one year after curative treatment and 23% experience chronic dysphagia [13]. Nevertheless, our survey showed that only few HNC patients (10%) are referred to OT by the hospital and often not until late effects are already present. A larger-scale register survey found that only 276 newly diagnosed HNC patients received a GOP in 2011 despite a general increase in the registration of GOPs for cancer patients [11], which corresponds to 20% of the 1,402 new HNC patients registered by DANCA same year [8].

Moreover, no doctors in our survey described that patients at their department are referred to OT prior to or during treatment, although research suggests that early exercise intervention has positive effects on quality of life and on the prevention of dysphagia [1, 9, 14].

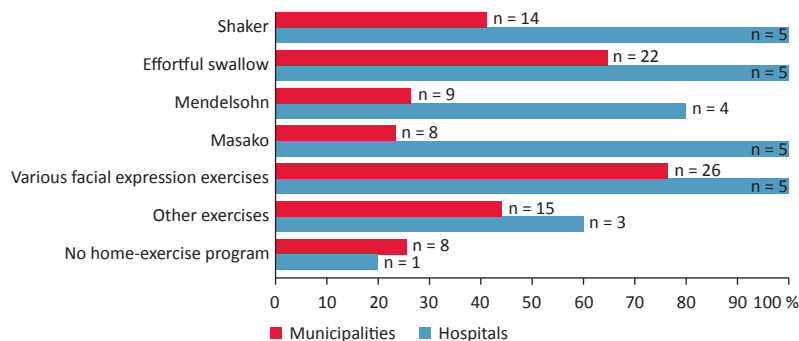
Several doctors expressed a need to differentiate between acute and chronic dysphagia and that it is not clear how dysphagia is defined. This, too, can have an impact on when, and if, the doctors choose to refer their patients to rehabilitation. Some doctors refer patients only if dysphagia cannot be attributed to acute radiation damage, thus choosing to wait and see how symptoms develop. This can have serious consequences for the patient, not least because sequelae, e.g. trismus, are very difficult to treat and to reverse once they have occurred [6, 12, 14-16].

Surely patients might reject rehabilitation despite medical judgments that he or she needs it, but the Danish Cancer Society's barometer survey documents that 49% of HNC patients who themselves experienced a need for physical rehabilitation did not receive the assistance they needed [17]. HNC patients are already vulnerable and do not always have the resources to ask for help, nor do they necessarily have relatives who can assist them. Patients who seek physical training on their own initiative after cancer are most often highly educated and/or young people, i.e. a group of people that harbours few HNC patients as HNC often affects persons above 60 years of age and persons with a low social standing [17-19]. This creates yet another divide in the rehabilitation offered to HNC patients.

Several studies have shown that self-administered or home-based exercises are difficult to establish in HNC patients who need support and guidance before a recurrent training programme can be left to the patient [9, 20]. Since sequelae still present themselves weeks or months after end of treatment, there is a need for ongoing evaluation of the patient's rehabilitation needs. In accordance with our survey, the Danish Cancer Society found that during a five-month period in 2010, 38% of HNC patients diagnosed for the first time with cancer

FIGURE 1

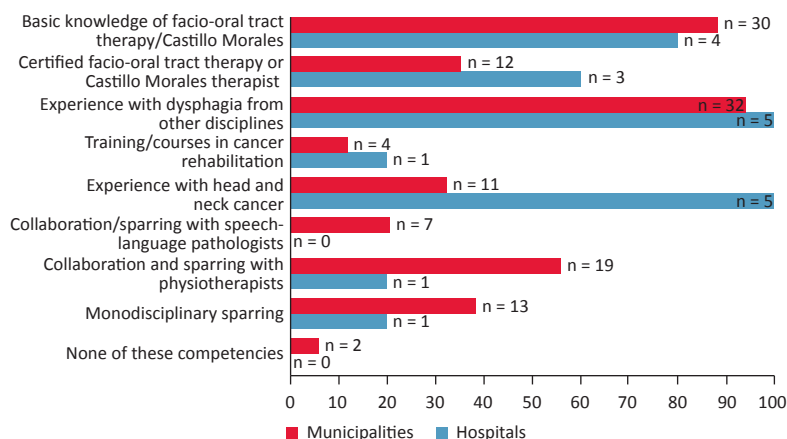
Selection of exercises in home-exercise programme for head and neck cancer patients. Share of occupational therapists in municipalities and hospitals, respectively, who instruct head and neck cancer patients in the listed exercises.



did not have their need for physical rehabilitation assessed by a professional at the hospital [17]. A vicious circle is created when no patients are referred to rehabilitation, the OTs do not develop their skills and the few patients who are actually referred will receive correspondingly less-skilled rehabilitation. Only in a few municipalities did the OTs make use of the exercises that have been shown to be effective in the rehabilitation of HNC patients (Figure 1). Instead they treated patients with Facio-oral tract therapy (FOTT) (Figure 2). The exercises listed in Figure 1 work by strengthening the pharyngeal constrictors and the muscles of the upper oesophagus, neck and hyoid, maintaining their range of motion and thereby improving the coordination, preci-

FIGURE 2

Which competencies do the occupational therapists in your institution draw on in their daily practice when they examine and/or train head and neck cancer patients with dysphagia? Share of occupational therapists who in municipalities and hospitals, respectively, who draw on specific competencies in their treatment of head and neck cancer patients.



sion, speed and safety of the swallow [1]. FOTT treatment, however, is designed for nerve stimulation and not for problems of e.g. fibrosis [5].

Apart from a 5-ECTS Diploma in Cancer Rehabilitation, which targets all health-care professionals working with cancer patients and focuses on interdisciplinary and sectorial teamwork, there is no specific cancer-oriented training for OTs in Denmark, let alone specific to HNC and dysphagia. Overall, OTs demand and require more education, research and knowledge sharing in the area of cancer, specifically HNC, in order to develop procedures and improve their skills to be able to perform a specialised rehabilitation be it in the municipality via regular GOP or in hospitals via specialised GOP. In either of the cases, HNC-related dysphagia calls for rehabilitation that is based on specialised competencies within occupational therapy.

Despite the official recommendations that specialised rehabilitation should be provided by OT in connection with initial treatment, such treatment is not provided regularly in the departments approached in this survey. The survey indicated that resources allocated to preventive therapy and intensive rehabilitation during hospitalisation are inadequate.

Due to the small number of doctors included in the survey, and since an unknown proportion of these have direct patient contact on a daily basis, it is difficult to generalise and conclude on physician and surgeon attitudes towards rehabilitation. However, the responding doctors were asked to provide their responses based on procedures in their department and not on their personal practices. It is expected that consultants and chief consultants possess adequate overview of in-house attitudes towards rehabilitation allowing them to provide representative answers. These answers show a lacking awareness of HNC patients' need for – and benefit from – rehabilitation prior to and after cancer treatment.

## CONCLUSION

The survey indicates that current Danish practice is probably not in line with the existing knowledge about preventive and rehabilitative actions in HNC nor with the legislation and recommendations in the field.

Despite the fact that guidelines and recommendations highlight the importance of early intervention before and after treatment, rehabilitation is often only initiated when sequelae are already present. Acute dysphagia affects 80% of HNC patients, and all patients should, according to current legislation, have their rehabilitation needs assessed prior to hospital discharge. Nevertheless, the majority of patients are discharged without a rehabilitation plan.

Dysphagia caused by HNC needs to be treated based on different principles than those commonly used

in neurology, but the knowledge and expertise is missing among the attending therapists, especially in municipality RCs. Since studies suggest that sequelae are more easily prevented than treated, extra efforts should be made to ensure that patients are informed of their rights and opportunities, and that they are supported intensively by therapists before, during and after treatment.

Rehabilitation in relation to HNC is an area with potential for improvements. Besides an increased focus on establishing rehabilitation plans and referrals, there is a need for more evidence-based research in dysphagia and HNC in terms of intensity, duration and exercises of the occupational therapy rehabilitation. If sequelae can be limited, then an intensified rehabilitation is a low-cost alternative to the high social and personal costs related to the increased care needs, adjacent complications and readmissions due to malnutrition and pneumonias caused by dysphagia.

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