Rehabilitation of head and neck cancer survivors: needs and barriers

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Head and neck cancer

• Life threatening ($60\% \text{ OS}_{5y}$)
• Located in an anatomic region important for
  – breathing, eating, communication, senses, appearance
• Rare: 6% of all cancers
Head and neck cancer

• Etiology: Tobacco, alcohol, virus (EBV, HPV), (occupational exposure)
• Treated with surgery, radiotherapy and chemotherapy or a combination
• Loco-regional control is the major challenge in tumor control
Head and neck cancer patients

• Viral or occupational etiology: ”One of us”
• Tobacco or alcohol induced
  – Co-morbidity, including psychiatric disease
  – Shorter education
  – Male sex
  – Fragile socio-economic position and work market affiliation
• Smoking prevalence and EBV sensitivity is higher in certain ethnic groups in Denmark, e.g. nasopharyngeal cancer patients in Denmark
(Chemo)-Radiotherapy

• Is the most prevalent treatment for cancers in the throat, and used for advanced cancer in the larynx, oral cavity, salivary gland and paranasal sinuses
• Usually 5½-7 weeks of daily treatments
• Side effects increase slowly during treatment
Common acute side effects

- Mucositis (burns)
- Sticky Saliva
- Taste alteration
- Nausea
- Pain
- Dysphagia
- Dehydration, weight loss
- Obstipation
- Pneumonia
- Worsening of comorbidity
Intense treatment course

Frequency of grade 3+4 toxicity (%)

- Dysphagia
- Skin
- Mucositis
- Tube feeding
Late side effects

- Dysphagia including aspiration
- Xerostomia
- Dental problems
- Fibrosis
  - Reduced neck and arm mobility
  - Trismus
- Impaired speech
- Disfigurement
- Osteoradionecrosis
- Hormonal alterations (thyroid and pituitary gland)
- Decreased hearing, vision and smelling
- Fatigue
- Undernutrition
- Social isolation
- Economical problems
Late Side effects – DAHANCA 6&7
Prevalence of grade 2-3 (n=1420)
Preparation for C-RT

Pre-habilitation

- Treatment of co-morbidity
- Geriatric assessment
- Smoking cessation
- Treatment of alcohol abstinence
- PEG or NG tube installation or use of nutritional supplements
- Tracheostomy
- Dental extraction
- Protocol inclusion!!
During C-RT
Supportive care- Keeping the patient alive...

• Close surveillance
• Active screening for nutritional or other problems
• Vigilant and specialized interdisciplinary team
• Pro-active use of analgesics and hospitalization
• Patient/ spouse education
After C-RT
Rehabilitation

• We use of minimal invasive surgical techniques and optimal surgical reconstruction as well as use of optimal radiotherapy techniques
• The choice of treatment determines late side effects
• Organ damage is often irreversible and fibrosis may be progressive over the years and rarely the cause of side effect can be treated

• So.....not really........much......
Rehabilitation

• Evidence is poor/ inconsistent for most rehabilitation intervention

• American Cancer Society: ”Most evidence not sufficient to warrant a strong recommendation...Consensus based management strategies”. Cohen. CA Cancer J Clin 2016;66: 203-
  – Level 1A: Accessory nerve palsy
  – Level 1A: Dental Surveillance, Carries
  – Level 1A: “General” rehabilitation (physical activity, tobacco abstinence etc.)
Why am I granted 25 minutes....?

• There is a very strong need for rehabilitation perceived by both patients, caregivers and professionals (and plenty of data!!)
• The severe physical, psychological, economical consequences of treatment combined with the poor coping strategies of the patients makes plenty of room for improvement
• There is a perception that the interventions work despite poor evidence
Absence of evidence is not evidence of absence

• Some issues especially relevant for head and neck cancer
  – Non-participation
  – Adherence/ compliance
  – Choice of endpoint
  – Choice/ description of intervention
  – Randomization/ blinding
Non-participation

- The patients with the most severe problems often do not participate in studies
Non-participation

N = 560 patients treated for cancers of the tongue, salivary glands, oral cavity, pharynx or larynx were invited to participate in the WebCan study between August 2011 and May 2013

N = 292 (52 %) declined to participate

N = 268 (48 %) accepted to participate

N = 189 (65 %) declined to participate, of whom n=24 actively refused and n=165 did not respond

N = 103 (35 %) declined to participate but agreed to fill in the baseline questionnaire

N = 134 Control group
N = 132 Intervention group

2 patients were excluded shortly before start of the intervention because of illness
## Non-participation

<table>
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<th>%</th>
<th>Participant</th>
<th>Decliners</th>
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<tr>
<td>Single</td>
<td>24</td>
<td>36</td>
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<tr>
<td>Short Education</td>
<td>12</td>
<td>25</td>
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<tr>
<td>Current Smoker</td>
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<td>Alcohol &gt;7/14</td>
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<td>40</td>
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<tr>
<td>BMI&lt;18.5</td>
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<td>14</td>
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</tbody>
</table>
Non-participants
Compliance

- Patients exercising >= 1 time per day

Choice of endpoint

- The effect of cancer and its treatment is multidimensional
- What is the best/right/optimal endpoint?
Choice of endpoint
Clinical significance of findings?

The DAHANCA 25B RCT-trial

Radiotherapy ± chemotherapy completion

2 months follow up

Randomization (n=41)

Group 1 (n=20)

Group 2 (n=21)

12 wk PRT

12 wk PRT

Baseline

LBM
Max. muscle strength
Functional performance
QoL and Fatigue
Blood sampling

12 weeks of Progressive Resistance Training is feasible in radiotherapy treated HNSCC patients and we found significant improvements over time in all primary and secondary endpoints:

- **Lean Body Mass**: ~4.8%
- **Muscle Strength**: ~20%
- (±) Functional Performance
- (↑) Quality of Life
Measures of side effects

Increasing patient relevance

ANALYTICAL MEASURE OF FUNCTION

SYMPTOMS

OVERALL MEASURE OF FUNCTION

OVERALL QUALITY OF LIFE

Increasing specificity
The intervention

• Well described intervention that doesn't fit everybody
• Poorly defined individualized interventions
• Multidimensional intervention
  – Cochrane Review: Multidimensional rehabilitation programs for adult cancer survivors

Swallowing exercises

Tongue hold
Hold the tip of the tongue between the front teeth with approximately 2 cm of the tongue outside the mouth. Feel a strong pull in the pharynx while swallowing. Repeat 10 times.

Gargle
Try to gargle as strongly as possible and pull the tongue as far back as possible at the same time. Hold the position for 10 seconds. Repeat 10 times.

Tongue range of motion
Open the mouth as much as possible while repeating the following 10 times in each direction.
1. Lift the tongue as high as possible behind the front teeth, hold 1 second, let go.
2. Lift the base of the tongue as high as possible, hold 1 second, let go.
3. Move the tongue along the upper teeth from one side to the other, hold 1 second, let go.
4. Move the tongue as far forward as possible, hold 1 second, let go.

Jaw exercise
Open the jaw as much as possible, repeat 10 times.
Move the jaw in circles, repeat 10 times.

Larynx range of motion
Breathe in and hold the breath while pushing 1 second. Relax and breathe gently. Repeat 10 times.
If the above is not possible say “a” hard and shortly 10 times.

Shaker exercise
1. Lie flat on the bed
2. Lift the head and look at the feet, keep shoulders down. Feel how the muscles under the chin are used. Hold the head-lift 1 minute.
3. Rest 1 minute
4. Repeat head-lift and rest 3 times in total.
5. Lift the head shortly and look at the feet. Repeat 30 times.

Falsetto exercise (if Shaker is not possible)
Move up the tone scale as high as possible to a high falsetto, hold the high tone as powerful as possible for 10 seconds. Repeat 10 times.
Randomization

- "Spontaneous" regression of symptoms i.e. randomization is often required
- Blinding is often impossible, but the endpoints are often subjective, making blinding/some comparator significant for the interpretation

de Graeff: Long-Term Quality of Life of Patients With Head and Neck Cancer
Every-day challenges with rehabilitation

- Epidemiology (age and HPV)
- Organization
- Resources
- Evidence
- Abuse, psychiatric disease, comorbidity
- Motivation – Patient, caregiver and professional
Motivation

• Many of our patients has been “resistant” to “rehabilitation” for ~60 years

-Artemis – Now I know what we should!
-What shall we?
-We shouldn’t
Please try anyway.....

......now, go out there and make some evidence....

Thank you!