



**WHO Collaborating Centre**  
for Evidence-Based Health Promotion in Hosp & HS  
**Bispebjerg University Hospital**



# Patient experienced side effects and adverse events after cancer treatment

## - Sequelae after radiotherapy for head and neck cancer

Sune Høirup PETERSEN, Bodil FELDINGER\*, Niels JESSEN\*, Helle KAUFMANN\*,  
Bolette PEDERSEN, Hanne TØNNESEN

\*Patient Network for head and neck cancer

WHO Collaborating Centre for Evidence-Based  
Health Promotion in Hospitals & Health Services  
Bispebjerg University Hospital



# Background

- Head and neck cancer are 6<sup>th</sup> worldwide and among the tenth most frequent cancer in Denmark with about 1000 new cases each year [\[i\]](#)
- The patient group as a whole are known to be negatively affected by socio-economic health determinants
- Head and neck cancer encompasses a variety of specific diagnosis defining the treatment modality: irradiation, surgery, adjuvant chemotherapy...

In Denmark

- Since 2003 treatment standardized in national guidelines
- In 2008 fast track pathways was guaranteed by a political decision

[\[i\]](#) Danish Cancer Registry.



# Background

- The most common treatment is radiation therapy, either alone or in combination with surgical intervention.
- Several of the side effects have been described after radiation therapy, the most common being dysphagia, xerostomia and hoarseness<sup>[ii]</sup>. The patients are informed that the symptoms are most pronounced during the first two weeks after radiation therapy reducing to about one to two thirds over the years<sup>[iii]</sup>.
- Acknowledge that there is patient reported side effects, which were not sufficiently detected by the objective side-effects measurement tools as well as common quality of life instruments<sup>[iv]</sup>

<sup>[ii]</sup> List MA, Bilir SP. Functional outcomes in head and neck cancer. Sem Radiat Oncol 2004; 14; 178-89.

<sup>[iii]</sup> Danish patient information material. Rigshospitalet, Copenhagen 2008.

<sup>[iv]</sup> Jensen K, Bonde A, Grau C: The relationship between observer-based toxicity scoring and patient assessed symptom severity after treatment for head and neck cancer. Radiother and Onco78 (2006) 298-305



# Motivation for Questionnaire

- Lack of realistic, official information about late side-effects
- Little focus on rehabilitation and alleviation of permanent conditions, which immensely affect peoples' lives (dental, speaking and eating problems), - also socially
- Questionnaire should provide the patient network with
  - Information about frequency and severity of late side-effects, as experienced by the patients
  - Documentation, in order to be heard politically and among professionals
  - Initial platform for elaboration of "real" patient-recognizable information



# Development of questionnaire

- Initial hearings in the network – resulting in a list of known late side-effects
- 1st draft of questionnaire made by Patient Network
- Professional assistance regarding wording and structure from experienced doctor (Hanne Thorsen), with specialty in elaboration of questionnaires
- Revised, professionally elaborated and tested on patients, resulting in 15 earlier versions
- Questionnaire forwarded to all 117 members of Network

# Collection and elaboration of answers

Questionnaire sent by letter to all members (117) of Network

- Response rate 66%
- The median age at treatment 55 years (range 24 to 81)
- Median 5 years post treatment (range 0 to 32)
- Respondents were 58% female and 42% male with 90% treated at two hospitals in the capital region
- More than 8 primary tumor sites
- Irradiation: unilateral 27%, bilateral 73%





# Results

- Analysis was performed to identify prognostic factors of the patient reported side effects surmised in themes.
- 99% patients experienced at least one side-effect, 67% more than twenty symptoms categorised into mouth complains, swallowing and eating problems, affected speaking ability, pain and fatigue during their daily living
- Ten years survival was the only significant prognostic factor OR 0.127 (CI 0.020-0.807)
- Only swallowing and eating problems were significantly reduced over time ( $p=0.048$ ) and in relation to calendar period (0.049), but not with increasing age
- Limitation: sample size, and the representational value of a patient network



# Conclusion

- The patients experienced pronounced sequelae, independent of gender, age and treatment/intervention
- Direct comparison to others studies are difficult due to differences in reporting and categorisation, but this patient developed study shows more pronounced sequelae to the literature/self-reported side effects
- Fast track pathways and treatment intensity guided by a multidisciplinary team to tackle acute toxicity are necessary, but the patient experiences reveal a need for long term assistance in coping with chronic sequelae



## Next...

- Results attracts interest from patients as well as relevant health professionals
- Systematic review of current patient information materials to identify key points
- Development of model for dialogue with relevant departments as to incorporate patient perspective and prioritisation
- Contributing to improvement of health literacy about late side effects even for the most disadvantaged of the patient group



**WHO Collaborating Centre**  
for Evidence-Based Health Promotion in Hosp & HS  
**Bispebjerg University Hospital**





**WHO Collaborating Centre**  
for Evidence-Based Health Promotion in Hosp & HS  
**Bispebjerg University Hospital**

