EAPC Research activities EPOS-NUF (Nutrition Fatigue): how to utilise multicentre research for additional projects





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Research in complex symptomatology – syndromes / diseases

Large data pools ("cohort studies") open opportunities to test hypothesis

AIDS-cohorts, Cancer-cohorts, ...

Decision on variables to be included: balance of "as much as possible" ←→ "pragmatic realistic"

Variables: essential → important → nice-to-have → do not know yet

Important hypothesis may raise late: be prepared

EPOS-Study: suitable as cohort study for nutrition & fatigue?

Patiens with cancer pain and opioid treatment Cross-sectional study, n=3'000 Multicentre, international, multilingual

Patient-reported: BPI, EORTC-QLQ-C30

Test with the patient: MMSQ

Sociodemographics Co-morbidity, tumor history

Opioids & pain history/Dg

Professional reported: Symptoms (and syndromes)

Status of opioid therapy

Biological samples: Serum, Edta (pre-analytics?)

EPOS-Study for N&F: Patient population

Cancer pain and "no" cachexia? Cachexia and no pain with opioid treatment?

- Pain (80%)
- Fatigue (90%)
- Anorexia (80%)
- Nausea (90%)
- Anxiety (25%)
- Dyspnea (50%)
- **Dizziness** (80%)
- Depression (30%)

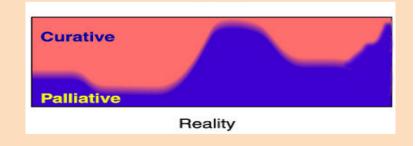
Volume 4 Topics Pall Care Walsh D Supp Care Cancer 2000 Vainio A J Pain Symp Manag 1996 Reuben DB Arch Intern Med 1988 Dewys WD Am J Med 1980 → Given the high frequency of anorexia it is likely that a majority of EPOS patients have anorexia/cachexia/fatigue

→ Various degrees

→ ",early" and ",late" cachexia

EPOS-Study for N&F: cross-section

Is the trajectory of anorexia/cachexia/fatigue too variable to allow for a cross-sectional design?



Research on symptom trajectories suggest fluctuation

→Include "longitudinal" questions in the cross-section

Weight loss history & dynamics

EPOS-Study for N&F: contents

Weight loss last 2 and 6 months

Estimation of nutritional intake: 1 question

FAACT: 12 questions

Single-item Fatigue: 4 questions

Checklist for secondary anorexia: 14 items

Treatments for anorexia/cachexia/fatigue: 1 page

Urine

EPOS-Study for N&F: hypothesis to test

Which questions relevant for nutrition & fatigue may be asked in this cross-sectional study?

Burning questions in anorexia/cachexia/fatigue in the palliative care context

Common standards for diagnosis of cachexia in palliative care

→ "Optimal" set of items to classify

Assessment instruments tailored to palliative care patients

- → Secondary causes of anorexia
- → Psychosocial, existential distress

Characteristics of early vs late cachexia: genomics

Characteristics of weight loss dynamics

Frequency of "palliative" nutritional issues: secondary and distress

EPOS-Study for N&F: hypothesis to test

Which questions relevant for nutrition & fatigue can NOT be asked in THIS study?

Burning questions in anorexia/cachexia/fatigue in the palliative care context

Common standards for diagnosis of cachexia in palliative care

→ "Optimal" set of items to classify

Assessment instruments tailored to palliative care patients

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Assessments going beyond (?) the features of the study:

- Nutritional intake
- Body composition
- Autonomic dysfunction
- Physical function measure

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EPOS-Study: Challenges

Challenges to "piggy-back" this large, intl. trial

Burden of assessments for patients, doctors, research nurses

Competition for additional modules

Variability of formats and time scales of instruments

Volume of biological samples (storage)

Legal issues: consent for main trial, but modules?

Translation of new assessment instruments

EPOS-NUF Study: Conclusion

An important opportunity to tailor additional modules to the backbone study

Distinguish collection of cohort data from evaluation of new assessment instruments

Decide upon requested sample size for specific modules evaluating defined questions

Consider to participate in the EPOS-NUF part



Thank you

many volunteers, coworkers, and colleagues (in research and clinic) my family

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