Background

In Norway, approximately 120 – 150 children and adolescents (under 15 yrs.) are diagnosed with cancer each year (Cancer Registry 2009)

Cancer diagnosis:

• A crisis for the child and the family

• Can give psychosocial problems and a poorer quality of life (QoL):
  - intensive medical treatment
  - stressors over a long period of time

• Can give a higher risk for cognitive, emotional og behavioural problems.... something which can influence them their whole life

(Koot & Wallander 2001; Last et al. 2005; Patenaude & Kupst 2005; Eiser 2007; Robinson et al. 2007)
Background
(cont.)

• Research about QoL, mental health and social functioning have shown varying and conflicting results for children and adolescents surviving cancer ¹

• Some studies report behavioural and emotional problems, learning difficulties and a poorer QoL than healthy children ²

• Other studies show that adolescents that survived cancer had a satisfactory or better QoL, mental health and social functioning ³

¹(Eiser et al. 2000; Sundberg et al. 2009; Zeltzer et al. 2009)
Children and adolescents
Goal

To explore and describe psychosocial health and QoL of children and adolescents surviving cancer at least three years after their cancer diagnosis, compared with a healthy control group.
Study population

Children and adolescents from 6-20 years were included in this study (N= 50 av 109):

• Surviving cancer at least 3 years after their diagnosis
• Treated at the Pediatric unit at St. Olavs Hospital, Trondheim, Norway
• In the period from January 1, 1993 to January 1, 2003
In addition to children surviving cancer the following also participated:

- One of the child’s parents
- A teacher
- A healthy control group
  - friend (same sex and age)
  - One of the friend’s parents
  - One of the friend’s teachers
Methods

Standardized questionnaires

- **Psychosocial health:** Strengths and Difficulties Questionnaire (SDQ)
  - 25 questions, 4 problemscales, 1 scale for prosocial behaviour

- **School functioning:** The Achenbach System of Empirically Based Assessment (ASEBA) – Teacher Report Form (TRF)
  - School and adaptive scales were used

- **QoL:** The Inventory of Life Quality in Children and Adolescents (ILC) and The Kinder Lebensqualität Fragebogen (KINDL)
  - 6 subscales/ life areas; physical and psychological well-being, selv-esteem, family, friends, school and a total QoL score

* Questionnaires sent to parents, adolescents and/or teachers

Methods (cont.)

In addition

There were questions about:
- Child’s diagnosis
- Length of treatment
- Health status
- Family’s socioeconomic status
Results

Psychosocial health: children and adolescents surviving cancer

Showed more emotional symptoms, higher total problem scores and poorer academic performance than the control group - especially those with brain tumors and late effects

Parents, teachers and adolescents reported the importance of their problems differently
Results


**QoL: children and adolescents surviving cancer**

- Adolescents reported a similar QoL compared with the adolescent control group
  - the exception were adolescents with brain tumors and late effects that experienced a poorer QoL

- Parents reported a poorer QoL, as well as several QoL domains being problematic for their own children compared with the parent control group
Results (cont.)

Children, adolescents and parent-proxy reports:

• Show that different perspectives provide a richer and deeper understanding about QoL

• Parson (1999) and Upton et al. (2008) emphasize that the main issue is not necessarily who is right, but what does both the reports contribute to our further understanding of QoL in children and adolescents?

• Thus, the main question will be how then can the information we receive from both the parent-proxy and self-report be used to guide and improve interventions enhancing well-being and long-term follow-up care in children and adolescents?
Conclusion and implications for clinical practice

To improve psychosocial health and QoL in children surviving cancer, the results show that:

• When planning long-term follow-up care, rehabilitation of children and adolescents with cancer should take into account the child’s psychosocial functioning and possible psychological problems
  - especially for those surviving brain tumors and late effects
Conclusion and implications for clinical practice (cont.)

For a better understanding, the results also show the need to take into account:

• Subjectively perceived and proxy-reported psychosocial health and QoL

It is important with different types of knowledge “evidence-based practice”:

• Experience-based knowledge
• Research-based knowledge
Great is he who knows, but greater is he who knows where to ask.

Piet Hein
Thankyou!

To the International Forum of Health Promotion Research

A special thankyou to all the children, adolescents and their families that gave of their valuable time!

Thankyou also to all professionals that do a wonderful job for these children and their families!