

## EORTC Cancer 1<sup>st</sup> Survivorship Summit Brussels, January 2014

I am just buying my Euros when the phone rings. Ordinarily I wouldn't pick up. This time I do. It's my oncologist: I have a recurrence. He will discuss options with me when I'm back. He mentions chemo, a possible trial...so this Brussels pan-European event on survivorship is timely. Thanks to Karen Inns I've been funded to travel to Brussels (though it's actually cheaper than some of my tickets to Leeds so I should stop being so parochial).

EORTC? It stands for European Organisation for the Research & Treatment of Cancer. Established for decades and pulling together many site specific studies, it created a Cancer Survivorship Task Force in 2013 ~ and now its first Survivorship Summit.

Some of the organising committee names are familiar: Neil Aaronson, from the Netherlands Cancer Institute had sat with Peter Rainey & I on Compass' Advisory Group. Many CSG members will also know Kathy Oliver from the International Brain Tumour Alliance. Jane Maher from Macmillan is on the programme as is Ollie Minton from St George's.

We have the Belgian Royal family and everything. (Princess Astrid is a patron.)

Patients and carers? Apart from Kathy, I'm not seeing many on the programme. Turns out there are some, both on the platform and in the audience. But not a lot, not by the standards we've become used to in the UK organisations like NCRI & NCIN. We find each other in that unspoken way we seem to have. It can't just be the lack of suits, can it?

### HEADLINES

- + Overall the tone is much more us and them, platform & floor, than we have become used to in NCRI & NCIN meetings.
- + Reinforces for me the value – and impact – of the palpably more collaborative approach that all parties here have worked so hard to engender and support in the UK.
- + New quality of life measures better suited to the needs of those living with and beyond cancer are in development: EORTC Quality of Life Group is tackling need for survivorship questionnaire, which will include cancer specific physical symptoms (swallowing, lymphoedema) & generic issues (return to work, fatigue, fear of recurrence).
- + Integrating evaluations of late effects to trials all the more important the more we learn about their prevalence & impact  
*"If we stop at 10 years we simply do not get the data."*
- + Systematic policy for long term follow up in EORTC trials
- + EORTC Survivorship strategy will see many new cross- country trials of interventions for e.g. fatigue
- + Increasing evidence of work difficulties post cancer
- + Enormous pressures from insurance industries for data sharing
- + Targeted therapies & second cancer risks will need new study design with international collaboration to put together patient groups and understand long term effects
- + All striking me, at least, as arguments for good patient/carer involvement in study design- and in helping set priorities in this expanding field.
- + More detail later in these notes for those who want it on Insurance, Work , Survivorship Programmes ,Fertility & Sexuality, other Late Effects & Fatigue

## DATA, DATA, DATA

Interesting accounts from Denmark where marrying classic registry & social data enables studies of social inequality in outcomes, of depression, and 20 yr cohort study of unemployment

- Outcome differences not in treatment but in compliance
- Problems a solely registry based study can not detect
- High incidence co morbidities evidence for need cross disciplinary study design

Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship (PROFILES) is a Danish registry for the study of the physical and psychosocial impact of cancer and its treatment, from a dynamic, growing population-based cohort of both short and long-term cancer survivors.

- Example: chemo induced neuropathy in population av. age 63  
1 in 3 report problems up to 10 years after diagnosis
- Open access to researchers
- Patient advisers & 20,000 patients are resource to help shape future studies – work is under way analysing their participant priorities for future research
- <http://www.profilesregistry.nl/>
- “*We’re not a Cancer Registry any more but a Cancer Patient Registry*”
- Findings have led to development of interventions: Impact!

## SOME BIG UNRESOLVED ISSUES IN THIS FIELD

- Fragmentation; too many small & underpowered studies
- WHO does not – yet- recognise Cancer Survivorship as a medical field
- World wide emphasis on more common cancers
- And we heard a lot about **those who do not take part** in studies – a larger % in Europe- what, one speaker asked, are *their* profiles & outcomes?
- How, I asked, can we best harness patient power to increase participation and access?

## PATIENT PERSPECTIVES

Kathy Oliver, excellent, powerful & well received presentation.

- Her list of topics for the future includes impact of diagnosis on family & friends, (including siblings of younger cancer patients), ramifications of recurrence, anticipatory grief & faster & more accurate diagnosis for rarer cancers.
- Clear & compelling case for patients as research partners, from very beginning, in evaluating proposals & design of studies, especially “soft end points”.

Read on for more on  
INSURANCE, WORK, LATE EFFECTS, SEXUALITY & FERTILITY, LIFE BEYOND  
CANCER, FATIGUE

Much of the first, scene setting, session is taken up with **INSURANCE AND DATA SHARING**, reflecting one of the emphases of survivorship discussions on the mainland, and one that might become more relevant to those of us in the UK. (*And indeed since writing these notes, of course it has, with the care.data implosion and questions about who gets access.*)

- 2/3 of those claiming on Critical Illness insurance policies are cancer patients ~and, to my surprise, the UK leads Europe in prevalence of the product. It's a £2bn industry.
- A patient speaker passionately tells us privacy isn't an issue – he wants everyone to have his data, offers to put his DNA on the Internet now; an unashamedly emotional approach, talking to an audience he assumes is made up of clinicians.

**"Somebody needs to give us the numbers."**

Insurance industry speakers make pleas for data.

- 50-year survival trends for childhood cancers/ data on increased risk of cardiac problems/evaluating the risk of a phase 2 randomised trial .....
- One speaker shows a lot of survival curves and a chart with figures from an underwriting manual for breast cancer. Showing how they price the risk.
- I'm finding some of this quite hard to hear. It's not the survival curves: I'm used to those. It's the tone; it's the lack of recognition there are patients in the audience.
- The language is getting to me: "*key value proposition of re-insurers* ".
- A speaker from a Manchester company stresses importance of travel to quality of life ~ he too is seeking better-informed underwriting, i.e. data so co's can assess risk.
- Distinct feeling there's a lot of lobbying going on: speakers are more aware of the person from the Commission than they are of patients in the room.

**WORK** after cancer, or in European speak, Labor Participation.

**"I've never felt so alone"**

- A Dutch survivor, Isobel Lebocqy, describes problems we survivors encounter: stigma and exclusion from employment and from finance (e.g. mortgages).
- We need to breakdown "cancer" into types & stages so support can be provided & employers educated.
- We need to change the way cancer is seen: recognise some will recover.
- This speaker sees what might look like good provision: Dutch employers obliged to pay 70% during 1<sup>st</sup> 2 yrs as leading to employer reluctance and to patients hiding diagnoses & history.
- Whereas work can bring benefits in recovery & self esteem as well as economic ones.

She cites a 2013 study of 700+ respondents: ¼ lost jobs, 50% of those got jobs again.

Isobel has established oPuce a social enterprise searching for real jobs for cancer survivors.

**"I almost had to beg employers".**

Later we hear about German studies which give evidence of

- Definite class effect on **return to work**
- Overall increased risk of both unemployment and early retirement.
- Positive consequences of work, at individual & societal levels

Debate is dominated by the insurers' data issues. They want access to new trial data and to registries, better to understand risk profiles. "and enable us to be more generous" to those who represent better risk.

Challenges from the floor show a gulf between the platform's approach and survivors' experience. "Our reality is not as nice as we have heard here".

A platform response to difficulty in obtaining cover "Work for a company with a good private health insurance plan" feels very out of touch and seems to reinforce privilege with privilege.

## LATE EFFECTS

A much more patient centred approach evident here ~ at last a speaker checks who is in the audience.

### EORTC Strategy for Cancer Survivors

- Creation of EORTC Survivorship Task force after 5 decades of large RCT's.
- Strategy includes getting late effects integrated into trials & systematic policy for long term follow up in EORTC trials
- Implications of studies on late effects: development of protocols with lower toxicities & equal therapeutic effect.
- Many questionnaires were constructed for those having treatment *now*
- So - big project to devise new QOL measures for survivors
- Survivorship projects – NHL then 9 trials on Hodgkin's = 6658 patients across 7 countries
- The fertility side of the story is what published so far
- Work, fatigue, social situation not yet analysed. But the data are now there
- And what about those patients who do not fill in the questionnaires? Or those who died? Data from Dr's?
- Data on over 20,000 patients on radiotherapy trials shows
  - Cardiovascular & pulmonary problems
  - Issues in Infertility & Sexuality
  - In cognitive dysfunction
  - And in psychosocial functioning

Lesley Schover from M D Anderson on priorities [in sexuality research](#)

- Treatment for sexual problems related to cancer treatment
- Early intervention
- Create comparative questionnaire looking at physiology & psychology of sexuality

And in [fertility](#)

- Euro registry of Biomarkers
- Patient centred & patient shared decision-making - what's effective?
- Post cancer parenthood decisions ~ whether and how to become parents after cancer treatment

In her experience fertility is a major issue for less than 10%. Sexuality can be up to 100%

["Few men have good sex lives after pelvic cancer "](#)

- Sexual problems rate highly in studies of unmet needs
- Less than 20% get help
- V few studies even mention in consent forms

- Women often go to gynaecologists: training need
- Few mental health professionals are trained in cancer & sexuality
- Excess sexual dysfunction among childhood cancer survivors
- When addressed it's very narrowly focussed in medical & hetero sexual terms
- Health care professionals need to be comfortable discussing and not see as a burden
- Research needs – effective interventions & methods of delivery group/peer /Internet?

*"The emotional impact of cancer related infertility doesn't go away"*

- Barriers to fertility preservation ~ cost: can patients access? Oncologists see as superfluous. Patient fears of delaying treatment
- Optimal care needs experts in clinic – people need to make rapid decisions at a very stressful time.

## LIFE BEYOND CANCER

### Survivorship programmes

Jane Maher described programme set up after recognition that 2m people in UK living with cancer.

- Piloting recovery package for newly treated patients with access back into the system via a trusted source
- Large no's thought not to need hospital based follow up
- Model is care plan & treatment summary developed after conversation with patient and sent to primary care
- Testing electronic version across 200 hospitals for final evaluation 2015

*"The conversation is as important as the tools "*

- Evidence from US & Canada: discussion about which tool to use is wrong focus
- Problem is reluctance to raise at the end of treatment when patients are ready to hear but professionals reluctant for fear of frightening the patient

### Behavioural & Life Style Interventions

*"Cancer can be a teachable moment. People are looking to take control back"*

- Issue: how to get cancer patients to access & use life style advice on diet/physical activity/weight? Interventions being tested.
- Evidence younger cancer survivors smoking at much higher rates than their peers
- And for those who do seek out information now, Internet sources are confusing.
- Need for services to provide good advice now recognised – but acted on?
- Cancer specialists don't know how to refer
- And *"those most in need of help are least likely to engage"*
- End of treatment not the only point – newer studies look at exercise during treatment.
- Evidence that breast cancer patients who stop or do less exercise during treatment never get back to same levels of activity.

*"It's the small things, not going to the gym but keeping going, walking every day."*

### Ollie Minton on fatigue studies

- Breast where a lot of the studies are being conducted
- Men catching up, i.e. this being recognised as an issue for men too
- Prevalence: 40% @ diagnosis / 60-90% of those on treatment /30% cancer survivors

- In recent multicentre survey fatigue the biggest problem for patients during treatment
- How intervene before becomes overwhelming?
- Methods for recording fatigue too varied within & across countries
- Cytokines drive symptoms - exact mechanism still unclear
- We don't know why it's happening & why in some individuals more than others
- Some evidence pro-inflammatory response
- Interventions ahead? Screening /evaluation /activity enhancement / psychological therapies such as CBT
- Evidence we do have - mostly from breast but now from prostate patients too, about **what's effective** in fatigue
  - Aerobic exercise – the earlier the better
  - Resistance exercise does not improve fatigue
  - Psychosocial & educational programmes
  - Acupuncture
  - Ginseng, American, one positive trial in high impact journal
- Clearer mechanisms would lead to more targeted treatments & better monitoring
- His wish list? Adding fatigue management to routine treatment monitoring  
STANDARDISED across tumour types. (Using 23 different fatigue measures really doesn't help.)

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