The Changing Cancer Patient Experience: What do we know and where should we go?

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Who am I?

• A public health professional
  • Professor of cancer epidemiology
  • Director of National Cancer Registry Ireland (NCRI)
  • Cancer researcher with emphasis an on the age-cancer relationship

• A person involved with cancer professionally & personally
The Changing Cancer Patient Experience

What do we know?

• People are living longer after a cancer diagnosis

• The cancer patient experience is increasingly about cancer survivors

• We collect limited data on the cancer survivor experience
Cancer Survivors

Combined 25+ years of survivorship!!
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Where should we go?

• Universal comprehensive survivor follow-up care

• Better understanding of the cancer survivor experience
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• Cancer used to be considered an acute disease
  • Cancer patients were commonly dying with little survival time
  • Incidence & mortality the major public health concerns

• Cancer is now considered a chronic disease
  • Cancer patients commonly have long survival times
  • Incidence & mortality important
  • Survivorship now a major public health concern
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Five-year Cancer Survival Rates in Ireland 1994-2014

- 1994-1998: 44.4%
- 1999-2003: 51.1%
- 2004-2008: 57.8%
- 2009-2013: 62.4%
- 2010-2014: 62.4%

https://www.ncri.ie/data/survival-statistics
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Five- & ten-year all cancer survival in Ireland 1994-2015

https://www.ncri.ie/data/survival-statistics
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Five year survival rates by cancer type, Ireland
Share of adults (aged 15-99), and children (aged 0-14) for leukaemia, diagnosed with cancer who survive at least five years following their diagnosis date. The year provided represents the year of diagnosis.

Source: Allemani et al. (2015)

https://ourworldindata.org/cancer
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Cancer survivors in Ireland 2016

breast 39,657
prostate 34,987
colorectum 20,608
melanoma skin 12,098
non-Hodgkin 7,390
lung 5,734
corpus uteri 5,424
leukaemia 5,226
bladder 5,004
kidney 4,741
tests 4,393
cervix 4,148
ovary 3,027
mouth & pharynx 2,931
thyroid 2,841
Hodgkin 2,657
stomach 2,135
brain & CNS 1,940
multiple myeloma 1,890
oesophagus 1,244
other gynaet 945
pancreas 765
liver 595

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• Higher survival rates related to major improvements in cancer prevention & treatment

• Screening tests find cancers earlier
  e.g. Mammography for breast cancer, Prostate Specific Antigen (PSA) for prostate cancer, Colonoscopy for colorectal cancer, Pap test for cervical cancer

• Existing treatments are being used in better ways

• Less side effects, which keeps planned treatments on schedule

• Newer treatments such as targeted therapy & immunotherapy
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The Cancer Journey

- Prevention
- Screening
- Diagnosis
- Treatment
- Recovery/Survivorship
- End-of-Life Care
- Psychosocial & Palliative Care
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The Cancer Journey

PREVENTION → SCREENING → DIAGNOSIS → TREATMENT

PRIMARY CARE

RECOVERY/SURVIVORSHIP

END-OF-LIFE CARE

PSYCHOSOCIAL & PALLIATIVE CARE
Understanding Survivorship

Cancer survivorship means living with, through, and beyond cancer.

Cancer survivors are people who receive treatment over a longer time. Their treatment can lower the chance of the cancer coming back or help to keep the cancer from spreading.

In Ireland there are nearly 170,000 cancer survivors. This is ~3.5% of the Irish population in 2015.
Understanding Survivorship

The phases of survivorship

Acute survivorship starts at diagnosis and goes through to the end of initial treatment. Cancer treatment is the focus.

Extended survivorship starts at the end of initial treatment & goes through the months after. The effects of cancer, treatment, recurrence, controlling spread of disease are the focus.

Long-term survivorship is when years have passed with continuing or completed treatment. Controlling spread of disease, long-term effects of cancer & treatment, recurrence, general health & secondary cancers are the focus.
Cancer Survivor Follow-up Care

• As more people are surviving cancer, how long a person lives is no longer the only focus. It is also becoming increasingly important to determine how well survivors are able to live after treatment.

• All cancer survivors should have follow-up care.

• Cancer registration should include data on what happens after diagnosis & initial treatment.
Cancer survivor follow-up care

- Controlling disease spread
- Watching for recurrence
- Managing late & long-term side effects of cancer
  - Bone, joint, soft tissue problems, Chemobrain, Digestion problems, Endocrine (hormone) system problems, Heart problems, Emotional difficulties, Lung problems, Lymphedema, Fatigue, Peripheral neuropathy, Secondary cancers, etc.
- Preventative medicine
- Maintaining a healthy lifestyle
- Managing other health problems
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How do we get there?
Continued emphasis on prevention, early diagnosis, improved treatments & cancer survivor follow-up.

• Integrated cancer follow-up plans for all patients
• Increased awareness of the importance of cancer follow-up
• National data for understanding/improving/setting policy for the cancer survivor experience
• ...
Thanks to ...

*You* – for being here & listening 😊

*Cancer patients!* – who’s experience it is

*NCRI staff* – for making data possible

*Hospitals, clinics & their staff* – for access to patient records

*Central Statistics Office & General Register Office* – for population & mortality data
More information at

www.ncri.ie  and/or  www.cancer.ie