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CANCER SURVIVORSHIP: Research informing service development

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I wish to acknowledge my research advisors Dr. Barbara Dooley, UCD, and Ms Ursula Bates, Our Lady's Hospice.

CANCER IN IRELAND

- Cancer cases yearly average 2007-2009 = 29,745 (NCRI, 2011)
- Expected increase of 72% in cancer rates to 2030 (WHO, 2012)
- Prevalence:
  - Estimates of 120,000 cancer survivors in Ireland
- Survival rates (> 5 yr relative survival rates):
  - IRL – all cancer average 54.6% – 56.5% (NCRI, 2011)
  - IRL – Prostate 88%; Breast 82%; Colorectal 55%; Lung 11%
  - US - 67.8% (NCI, 2009)
  - EU - range = <20% - 80% (Bernini et al., EURDCARE-4, 2007)

Who is a cancer survivor?

- “... from the time of its discovery and for the balance of life, an individual diagnosed with cancer is a survivor” (All Nations Edition of Cancer/Bantu, 1986)
- “...people who have been diagnosed with cancer and the people in their lives who are affected by their diagnosis, including family members, friends and caregivers” (Cancerwise Ireland: NCI, 2006)
- “...are living apparently free of cancer at any time after treatment” (Cancerwise Ireland: NCI, 2006)
- “The individual who is at least 18 months post medical treatment for cancer” (The CANSURVIVOR Project)

Survivorship

- Positive adaptation after cancer: “A full and enthusiastic return to the normal activities of life.” (Spencer et al., 1998; 212)
- “Survival” does NOT mean a return to ‘Normal’ for all:
  - ~20% experience negative/long-term or late effects (Ganz, 2003)
    - Psychological: body image, fear of recurrence, anxiety
    - Physical dysfunction: fatigue, pain, reduced activity, weight gain
    - Vocational issues: disruption to work, family life & finances

Survivors Need (Ganz, 2007; Aziz, 2007)

- Care
- Information and Education
- Assistance with rehabilitation and lifestyle issues
- Structured psychosocial and educational interventions
- What about Irish survivors?

Survivorship in Ireland

- Profile of Irish cancer survivors?
- QoL outcomes?
- Health behaviours? Risk?
- Service needs?
- Effects of SES on burden of recovery?

The CANSURVIVOR Project

Building an evidence base in Ireland

- Investigate life after cancer
- Profile quality of life and health behaviours
- Identify service needs
- Develop, implement, evaluate multi-disciplinary rehabilitation/survivorship programme
- Report and Recommend, Disseminate & Adopt

- HSE-East Coast area (SVUH)
  - Breast, Colorectal, Prostate, Lung cancers
  - Cancer ‘primary diagnosis’
  - Post-treatment - min 6 mths
  - 3 studies
Study 1. Exploring Life After Cancer Treatment

Participants (n=56):
- Male & Female survivors (18);
- Carers of survivors (4);
- Cancer Health Professionals (2);
- Cancer Support Groups Representatives (32)

Speak about the experience in terms of:
- Physical, Psychological/Emotional/Social/Vocational impact
- Speak about possible effects of Socio-economic status
- Speak about Service issues

Study 1. The Issues

Professionals
- Depends on treatment, Physical effects.
- Lack of knowledge of ‘life after cancer’

Carers
- Support gap, Whole family fear, Vocational effects on family.
- Financial support issues, Lack of information of ‘life after cancer’

Cancer Survivors
- Fear of recurrence, Anxiety & Depression, Stress, Fatigue, Body image, Financial implications, Vocational effects, Changing roles, The need to talk to someone, Lack of information of ‘life after cancer’

Survivorship Workshop

- Fatigue
- Bone pain
- ‘Chemo brain’
- Changing home life - need practical help – carers
- Lack of access to prosthetic services
- Going back to work
- Excesses too high
- Damaged career prospects

“Anxiety pain”
- Worry of relapse
- Sexual dysfunction
- Appearance/body image
- Anger
- Denial
- Guilt
- Social isolation
- No long-term follow-up

Lack of Written Information

Study 1: Summary of findings

Salient issues for survivors:
- Anxiety & fears about recurrence, fatigue, lifestyle changes, changes to social relationships and the impact of economic status
- Existing follow-up services are inadequate, inconsistent, lacking co-ordination - a poor experience for survivors
- There is a need to Educate health care professionals about post-treatment issues.
- Provide good quality written information for survivors about ‘life after cancer’.
- Fill the service gap to deal with long-term and late effects

Inclusion criteria:
- Breast, Colorectal, Prostate & Lung Cancer survivors
- HSE-East Coast area (SVUH)
- TNM Criteria - Stages 1, 2, 3, M=0
- Cancer is ‘primary diagnosis’
- Post-medical treatment by min 6 months

Exclusion criteria
- < 18yrs or >75 yrs
- No psychosis

A comprehensive survey of survivors
N=262 (response rate 33.8%) (70 males; 192 females)
Mean time since tx 4.44yrs.
Assessed quality of life, anxiety, depression, positive mental attitudes and several health-related beliefs and behaviours (diet, exercise behaviours, etc.)
Study 2: Quality of Life & Needs Analysis

- Up to 26% had significantly poor quality of life in terms of functioning and symptoms
- Anxiety and health behaviours are major issues
- Very little contact with allied health professionals as in-patients

Participants views on services:
- not interested in emotional impact of cancer,
- no helpful advice on diet,
- expected to feel positive,
- no information on support services,
- no financial help

<table>
<thead>
<tr>
<th>Functioning</th>
<th>% (n)</th>
<th>Symptoms</th>
<th>% (n)</th>
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<tbody>
<tr>
<td>Physical function</td>
<td>19.8% (52)</td>
<td>Insomnia</td>
<td>26.5% (69)</td>
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<tr>
<td>Global Quality of Life</td>
<td>15.4% (40)</td>
<td>Constipation</td>
<td>24.7% (64)</td>
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<tr>
<td>Emotional functioning</td>
<td>15.4% (40)</td>
<td>Diarrhoea</td>
<td>16.9% (44)</td>
</tr>
<tr>
<td>Social functioning</td>
<td>11.9% (31)</td>
<td>Low appetite</td>
<td>13.0% (34)</td>
</tr>
<tr>
<td>Role Functioning</td>
<td>11.1% (29)</td>
<td>Pain</td>
<td>12.6% (33)</td>
</tr>
<tr>
<td>Cognitive function</td>
<td>5.8% (15)</td>
<td>Fatigue</td>
<td>11.0% (30)</td>
</tr>
<tr>
<td>Cognitive function</td>
<td>5.8% (15)</td>
<td>Dyspnoea</td>
<td>9.3% (24)</td>
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<tr>
<td>Cognitive function</td>
<td>5.8% (15)</td>
<td>Financial impact</td>
<td>8.5% (22)</td>
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<tr>
<td>Cognitive function</td>
<td>5.8% (15)</td>
<td>Nausea and vomiting</td>
<td>6.9% (18)</td>
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Percent of participants > 1 SD below Mean on function & > 1 SD above Mean on QoL symptoms

Comments on Services

“Absolutely no back up unless you look yourself”

“During the treatment they were very good, but when you think you feel you have been set adrift and your lifeline is gone.”

“Once I had left the hospital there was no back-up and it was only through my own endeavours that I finally got my life back on track.”

“During my treatment and about 2 yrs after I was ok. Then it seemed to hit me, what happened to me and I fell apart. I would like to have known this might happen”

“Being constantly told there are things you can’t do…”

Participants view:
- Services not interested in emotional impact,
- no helpful advice on diet,
- expected to feel positive,
- no information on support services,
- no financial help
Cancer survivors need:
- Information about the post-treatment phase
- A structured, co-ordinated service to enhance quality of life in terms of functioning and symptom management
- Specific help with dietary change, weight & anxiety reduction and increasing physical fitness & activity levels.

Health professionals need:
- To increase their knowledge of life after cancer
- To acknowledge the emotional impact of cancer
- To guide survivors towards positive behaviours – tell them what they CAN do

Maximizing Quality of Life:
- Intervention development must be evidence-based
- Addressing both disease and treatment effects
- Attempting to reduce risky health behaviours, behaviours and coping
- Take a Bio-Psycho-Social rather than a Biomedical approach

Study 2. Conclusions

Study 3. Pilot program Design
- Treatment group (n=22), Comparison group (n=16)
- Breast, prostate, colorectal survivors; Mean age = 58.2; Tx end = 4.18 yrs
- 8 weeks
- Screened pre and post program
- Evaluated by Service Users + Service Providers

Program Curriculum - Multidisciplinary
- Hope Therapy (based on Cheavens et al, 2006)
- Physical Activity Module
- Nutrition Module

Results
- Significant \( \triangle \) in qol functioning and \( \triangle \) in qol symptoms
- Significant \( \triangle \) in anxiety, weight, saturated fat intake
- Significant \( \triangle \) in fitness, strength, physical activity, fruit & vegetables and fibre intake, hopeful thinking

Study 3 - Conclusions

Research Findings
- The intervention positively impacted on quality of life
  - Improved functioning
  - Reduced symptoms
  - Positively impacting on factors influencing future physical and mental health
- The positive and integrated programme received a very positive evaluation from both participants and the delivery team
  - Recommended access to programme earlier in the post-treatment phase
- Survivors need information and services aimed at enhancing quality of life and maximizing physical and mental health
- The pilot intervention was excellent in enhancing quality of life and in helping to make positive lifestyle changes

Figure 3. Changes in Dietary variables

Figure 4. Changes in Physical Activity variables
Using Research Findings
Turning Knowledge to Action

- KT – a slow and haphazard process (Agency for Health Research & Quality, 2001)
- Optimum application of what is already known could improve cancer outcomes by ~30% (Canadian Strategy for Cancer Control, 2001)
- Research Values vs. Practice Values - successful translation of research requires researcher-practitioner collaboration to improve quality of survival
- The RE-AIM and Knowledge to Action (K2A) frameworks are useful for research translation into practice (Pollack et al., 2011)

Next Steps to Improve Outcomes

Dissemination
- Publication/advertising of findings
- Influencing survivors & healthcare providers to receive, accept and use information & interventions

Translation
- Effective and widespread use requires development of guidelines, changing current practices, evaluating outcomes of change across a range of contexts

Key Efforts Necessary for Improving Life After Cancer
- Develop information resources for survivors, carers & practitioners
- Develop services: care plans, psycho-educational interventions for those who want it and survivorship/ rehabilitation programmes for high risk groups

If you feel like reading


And in the end, it’s not the years in your life that count. It’s the life in your years”

Abraham Lincoln

Thanks for your time

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