CANCER SURVIVORSHIP: Research informing service development

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22nd Oct 2012

The CANSURVIVOR research project was funded by the Health Services Executive, Dublin Mid-Leinster

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% (Berrini et al., EUROCARE-4, 2007)
Who is a cancer survivor?

“The individual who is at least six months post medical treatment for cancer
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:
  - Expectations 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
Professionals

“We deal with the physical side…we are not delving into anything much deeper than that.”

Female Survivors

“The fear never leaves you”; “You tend to think everything is cancer”

Male Survivors

“Your lifestyle is changed completely”; “You can’t play rugby, lift heavy things”

“Your bathroom is totally different than it was before. You’ve got odours, you’ve got stuff lying around the place and you’ve got to be conscious of people coming into the house”
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
Study 2: Quality of Life & Needs Analysis

**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
Figure 1. Health Risks
Figure 2. Mean Quality of Life score in each functional domain EORTC
Scale range 0-100
Higher Score = Better Quality of Life
Figure 3. Mean Quality of Life symptom scores EORTC

Scale range 0-100
Higher score = Lower Quality of Life
### Percent of participants > 1 SD below Mean on QoL function & > 1 SD above Mean on QoL symptoms

<table>
<thead>
<tr>
<th>Functioning</th>
<th>% (n)</th>
<th>Symptoms</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>19.8%(52)</td>
<td>Insomnia</td>
<td>26.5%(69)</td>
</tr>
<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 functioning</td>
<td>5.8%(15)</td>
<td>Fatigue</td>
<td>11.6%(30)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dyspnoea</td>
<td>9.3%(24)</td>
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<td></td>
<td></td>
<td>Financial impact</td>
<td>8.5%(22)</td>
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<tr>
<td></td>
<td></td>
<td>Nausea and vomi</td>
<td>6.9%(18)</td>
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</table>
“Absolutely no back up unless you look yourself”.

“During the treatment they were very good, but when you finish 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
• Increase positive health-enhancing beliefs, 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 \( \Delta \)qol functioning and \( \Delta \)qol symptoms
- Significant \( \Delta \) in anxiety, weight, saturated fat intake
- Significant \( \Delta \) in fitness, strength, physical activity, fruit & vegetables and fibre intake, hopeful thinking

Attrition 21 / 22 completed

Attendance 76.5%
Figure 3. Changes in Dietary variables
Figure 4. Changes in Physical Activity variables
Study 3 - Conclusions

- 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
Research Findings

The quality of life of Irish cancer survivors is impacted by significant late and long-term effects from cancer. Survivors need information and services aimed at enhancing quality of life and maximizing physical and mental health. The pilot intervention was successful in enhancing quality of life and in helping to make positive lifestyle changes.

To optimize survivorship where do we go from here?
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
“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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