Improving Communication and Understanding the Needs of Women Diagnosed with Life-Threatening Cancers

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Social work in health

• **Historical significance**
  ◦ *Dr Ida Cannon and Dr Richard Cabot*

• **Shift in focus**
  ◦ *from infectious disease to chronic disease*
  ◦ *Ageing population*
  ◦ *Prevention and community management*

• **Shift in outcomes**
  ◦ *Patient experience*
  ◦ *Patient engagement and focus*
  ◦ *Clinical decision making*
  ◦ *Reduction in re-presentations and bed days*
  ◦ *Barriers and access to care*
Outline of presentation

Relationship between ‘distress’ and ‘adjustment’ as a response to cancer

- Practice research issue
- Practice research question
- Research studies-
  - Clinical Data Mining
  - Qualitative Study
  - Quasi-experimental trial
  - Stakeholder focus groups

- Recommendations for practice

*co-creation harnesses the transformative potential of dialogue across difference and empowers participants as co-learners or co-researchers*
Academic Practitioner Collaboration

- Focus on *practitioner identified* issues
  - Shared clarification of issue
  - Shared development of research question
  - Decision on research methodology and design
  - Practice issues and political significance

*Results disseminated back into practice*
Definition of Supportive care in Cancer

‘ the provision of the necessary services for those living with or affected by cancer to meet their –
  ◦ Informational
  ◦ Emotional
  ◦ Spiritual
    ◦ Social
  ◦ Physical needs

during their diagnostic, treatment or follow-up phases ’

Supportive care screening is a statewide policy directive –

But - 
*screening is not diagnostic*
Worry nervousness fatigue fear sadness have the highest prevalence in screening – are these mental health issues suggesting the need for a mental health intervention?

OR

An indication of adjustment to a diagnosis of cancer?

Relationship between SCST scores and adjustment disorder
Evidence from the literature - Adjustment ?

- Adjustment disorder in 12.4% of newly diagnosed cancer patients N= 15,000 (Mehnert et al 2016)
- Over 40% with 1 or more adjustment behaviours
  - Transient
  - Associated depression and anxiety
  - Social and occupational impact
  - Cognitive disturbance
Relationship between social and emotional distress
Stress  Support

Carers
Factors contributing to positive Carer experience

- Extensive family support
- Access to community resources
- Deeply committed relationship
- Carer health and wellbeing
- Competence in caring
- Carer life stage
- Vocational benefit
Factors contributing to extreme Carer distress

- Unrealistic family expectation
- Life stage
- Carer burden
- Carer unsupported
- Conflict in relationship
- Carer health issues
- Carer adjustment to diagnosis/prognosis
Change in Social Situation

On presentation
- Office of Housing
- finances
- symptoms-confusion
- Ex-husband
- son 19yrs
- dau 17yrs identified carer

After SW intervention
- Office of Housing
- Financial administrator
- Ex-husband
- son 19yrs
- dau 17 yrs
- 15 and 9 year old daughter

Symptoms-reduced confusion
- mother and 2 sisters estranged
- VCAT-guardian-protection
- Community packages
- rehab
RWH health services innovation trial

**Phase 1: Preparation**
- Scoped literature and developed theory
- Refined research aims, objectives, questions
- Established an Advisory Group comprised of key partners
- Refined data collection methods
- Developed an engagement strategy for patients
- Developed a training and supervision package for nurse coordinators
- Obtained ethics approval

**Phase 2: Baseline & Intervention**
- Monitored patient pathway of 65 patients
- Distress screening tool referral as usual
- SoNETQ administered
- Implemented SF36 on exit
- Prospect patient experience questionnaire administered

**Phase 3: Results**
- Synthesised and analysed all data collected
- Produced final report
- Presented results to partners, stakeholders and interested participants
<table>
<thead>
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<th>Distress Score</th>
<th>Percentage</th>
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<td>&lt;3</td>
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<td>R-squared</td>
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<td>-----------------------------------</td>
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<td>Financial</td>
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<td>Close personal relationships</td>
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Themes central to the intervention

- Health literacy
- Adjustment and reduced distress
- Social relationships
- Social context
- Informed decision making
Comparative qualitative analysis of themes (N=120)

- Information about my diagnosis
- Information about my treatment pathway
- Telling family and friends about my diagnosis
- Understanding the future in relation to my diagnosis
  - Person Health Literacy
- My relationship with family.
- Planning my life in relation to treatment
- Connected socially to my friends
  - Acknowledgement of personal identity
- Being in control of my life
- Professional services that I have received for emotional support
- Money and managing my finances
  - Clinical decision making
- Child bearing, parenting and grand-parenting
- Managing the side-effects of treatment
- Connected to culture and religion
  - Staying connected ....
Sensitivity and specificity of the supportive care screening score

Sensitivity

Specificity
Identified areas of need - distress screening scores of 4 or less
Identified areas of need - distress screening scores of 4 and 5
Identified areas of need for the 14 patients with MyNE scores 6 and above.
Survivor – service request

Women with cancer – needs and decision making

Outcome data from social intervention
Next steps –

- digital
- evidenced
- social factors contributing to health
  - on hospital databases


