Lost in translation?
Cancer nursing in a future that is not what it used to be

Mary Wells
Professor of Cancer Nursing Research & Practice
NMAHP Research Unit
University of Stirling
The Development of Cancer Nursing as a Speciality*

Robert Tiffany

Int. Nurs. Rev. 34, 2, 1987
• What is special about cancer nursing
• What can get lost in translation
• What the future might hold for us
• What contribution cancer nurses can make to the translation of patients’ experiences in practice and in research
Too Posh to Wash?
Reflections on the Future of Nursing
January 2013
Edited by Gail Beer
With a Foreword by Jeremy LeFroy MP for Stafford
Lost nursing care

Data from 33,659 nurses in 488 hospitals across 12 European countries

The value of nursing

Cancer Patient Experience Survey 2011/12

National Report

Department of Health
You don’t like asking for things because you think it’s silly... you feel it’s minimal you know, it’s only feeling sick, like a slight headache, so what?... or you feel tired, so what?... they’re only minimal things... the cancer’s the big thing... having a headache, not sleeping, they’re minor things so you don’t want to say anything about that
“The future is not what it used to be”

Paul Valery

French critic & poet (1871 - 1945)
Survival is improving
The % population over 65 will rise from 17% in 2010 to 23% in 2035 (UK) and % from 21% to 31% (Germany).

UN 2012; Office for National Statistics 2012
Comorbidity

• Multi-morbidity increases with age and socioeconomic deprivation (Barnett et al, Lancet 2012)

• Comorbidity in the context of cancer is associated with
  – delay in diagnosis
  – ‘under-treatment’
  – treatment complications
  – poorer survival (Søgaard et al Clinical Epidemiology 2013)
• At least 1 in 4 people living with cancer face poor health or disability as a result of cancer treatment
• Survivors at greater risk of second malignancies, serious adverse health events and chronic conditions
• 53% had ≥1 moderate to severe unmet need 6 months after diagnosis (Armes et al 2009)
• Survivors of cancer more than twice as likely to report poor health, reduced activity and psychological morbidity (Evans et al 2011)
Delivering High-Quality Cancer Care: Charting a new course for a system in crisis

Institute of Medicine 2013

The Crisis

“Cancer care is often not as patient-centred, accessible, coordinated, or evidence-based as it could be, detrimentally impacting patients”

• Aging population, ↑↑ survivors
• Workforce shortages, inadequate training and preparation
• ££$$€€ significant and rising
• Increased understanding of biology → increased complexity of treatment
• Tools for quality improvement not widely enough used and not fit for purpose
The future is not what it used to be

Cancer leaves no aspect of life untouched
(Frank 1981)
Lost in translation?

Navigating your way through cancer and its treatment is rather like being dropped in a strange city without a map or compass. There are no landmarks you recognise and no familiar features. This city has no signs, no one speaks your language and your requests for help are incomprehensible: they are unable to help you.

Rachel Clark 2002 A long walk home
beating bowel cancer now!

awareness education support
Figure 2. The Emergent Integrated Circuit of the Cell

- Ability to work
- Ability to go out for a drink or meal
- Financial worries
- Eating problems
- Sexual problems
- Emotional difficulties
- Need to frequently use toilet
- Loss of self
- Changes in appearance
- Pain
- Anxiety and depression
- Fears of recurrence
- Functional changes
- Cognitive changes
- Physical side effects of treatment
- People talk to you differently

Note: The diagram illustrates various aspects of treatment-related issues with labels like 'Physical side effects of treatment', 'Cognitive changes', 'Changes in appearance', 'Loss of self', 'Pain', 'Anxiety and depression', 'Fears of recurrence', 'Functional changes', 'Emotional difficulties', 'Ability to work', 'Ability to go out for a drink or meal', 'Financial worries', 'Eating problems', 'Sexual problems', and 'People talk to you differently'.
UK Cancer Research Spend

A Randomized Controlled Trial to Evaluate the Effectiveness of a Brief, Behaviorally Oriented Intervention for Cancer-related Fatigue

Jo Armes, PhD, MSc, BSc, RGN
Trudie Chalder, PhD, MSc, RMN
Julia Addington-Hall, PhD, BSc
Alison Richardson, PhD, MSc, BN, RN
Matthew Hotopf, PhD, MSc, MRCPsych, MBBS, BSc

BACKGROUND. It has been shown that nonpharmacologic interventions are effective management techniques for cancer-related fatigue (CRF) in cancer survivors. However, few studies have investigated their effectiveness in patients who are receiving chemotherapy. In this study, the authors tested the effectiveness of a brief behaviorally oriented intervention in reducing CRF and improving physical function and associated distress in individuals who were receiving chemotherapy.
Nurses can get practice into research

“The aim should not be to perfect techniques of feeding results to decision-makers, but to start from the perspective of the decision-makers even before devising the questions. This means ‘getting practice into research’”

The pursuit of F-A-M-E

What are patients’ experiences of cancer and cancer care?

How can we prevent, ameliorate and manage these problems?

What interventions work, how why and in what contexts?

How can we assess experiences and problems more effectively?

Whom do we need to target?

Feasible, Acceptable, Meaningful and Effective interventions
Qualitative meta-synthesis

- Systematic
- Rigorous
- Rich
- Provides basis for practice and intervention development
The psychological experience of living with head and neck cancer: A systematic review and meta-synthesis
Lang, France, Williams, Humphris, Wells (2013)
Psycho-Oncology
A conceptual model of the experience of cancer and work (Wells et al 2012 Psycho-Oncology)
Symptom experiences after cancer treatment

Themes:
• Interaction with health services
  – Communicating symptoms and concerns, feeling unprepared, fears of the future
• Changing relationships
  – Family, friends, sexual relationships
• Changing self
  – Changed bodies, changed minds, losing independence
• Ways of coping

‘Lines of action’:
• Improving communication
• Acknowledging life context
• Symptom clusters, co-morbidities and under-researched symptoms
• Emotional recovery and return to work

Bennion & Molassiotis
Support Care Cancer (2013) 21:9-25
Assessing experiences and outcomes more effectively

- Choosing appropriate outcome measures and appropriate time frames
- Understanding the context
- Asking the right questions

*Which way should I go?*

*That depends a good deal on where you want to get to.*

Alice in Wonderland by Lewis Carroll
Depends how you ask the question...

<table>
<thead>
<tr>
<th>Most common concerns in HNC survivors</th>
<th>Most important concerns</th>
<th>Concerns for which more help and support was required</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Dry mouth</td>
<td>1. Dry mouth</td>
<td>1. Dry mouth</td>
</tr>
<tr>
<td>2. Fatigue / tiredness</td>
<td>2. Fear of recurrence</td>
<td>2. Fear of recurrence</td>
</tr>
<tr>
<td>3. Fear of recurrence</td>
<td>3. Fatigue / tiredness</td>
<td>3. Fatigue / tiredness</td>
</tr>
<tr>
<td>5. Swallowing</td>
<td>5. Swallowing</td>
<td>5. Swallowing</td>
</tr>
</tbody>
</table>
The information you have is not the information you want.
The information you want is not the information you need.
The information you need is not the information you can obtain.

73% trial data unused (O’Leary et al 2013)

Against the Gods. The remarkable story of risk
Peter L Bernstein 1996
RE-AIM & the law of halves

50% continue to benefit 6 months later
1.6%

Russell Glasgow
www.re-aim.org
Intervention description is not enough: evidence from an in-depth multiple case study on the untold role and impact of context in randomised controlled trials of seven complex interventions

Mary Wells¹, Brian Williams², Shaun Treweek³, Joanne Coyle⁴ and Julie Taylor¹,⁵
To fully realize the benefits of personalized medicine, advances in genomics will have to be complemented with advances in research in patient-centred care so that personalized medicine is practiced within the context of healthcare delivery systems that are responsive to the needs of patients and their family members and empower patients to play an active role in their healthcare.

“I need to know that this is my body. And I need to know everything that is happening to my body. But most of all I need to know that you know that within my body there is me”

Michele Angelo Petrone
MARY WELLS

"I SEE A FUTURE IN YOU"

Arranged by
Sunny Linno
George Jackson
Strings & Vocals
Arranged by
Charles Chalmers

Produced by Sunny Linno
Rick Hall

Backed by "Memphis" 
(Pete Burns and Stu Shant)

Reprise Records
1031
2:38
Promotion

NOT FOR SALE

Fame Publishing, Inc.
BMI
And thanks to my granny, Susan Richmond, for her inspiration.

1915 Scottish Women’s Hospital, Royaumont, Paris