Nurse led cancer care: looking to the future

Mary Wells
Professor of Cancer Nursing Research & Practice
The value of nursing

Person-centred care

holistic

individualised

empowering

respectful

A concept analysis of person-centred care
Morgan et al Jnl Holistic Nurs 30,1, 2012
‘I wanted to say a huge thank you and (show) appreciation for your amazing patient care, commitment and understanding that I received in my appointment. I have to say that the appointment was different to any I have experienced before. When I left my consultation I had a fantastic feeling that I had someone that actually connected with the issue(s) I had and understood them as well as I experience them, this is a very rare quality.

I personally feel that having someone that understands and connects with the medical condition you are experiencing, is just as important as receiving a prescription/treatment for the aliment. This may sound a small statement but it’s actually a big relief for a patient.’

Male cancer survivor (38 years of age), with complex health needs as a result of previous treatment, including bone marrow transplant received at age 17.
The value of nursing

Nurse staffing and education and hospital mortality in nine European countries: a retrospective observational study

Linda H Aiken, Douglas M Sloane, Luk Bruyneel, Koen Van den Heede, Peter Griffiths, Reinhard Busse, Marianna Diamidou, Juho Kinnunen, Maria Kozka, Emmanuel Lesaffre, Matthew D McHugh, MT Moreno-Casbas, Anne Marie Rafferty, Rene Schwendimann, PA Anne Scott, Carol Tishelman, Theo van Achterberg, Walter Sermeus, for the RN4CAST consortium

Summary

Background Austerity measures and health-system redesign to minimise hospital expenditures risk adversely affecting patient outcomes. The RN4CAST study was designed to inform decision making about nursing, one of the largest components of hospital operating expenses. We aimed to assess whether differences in patient to nurse ratios and nurses’ educational qualifications in nine of the 12 RN4CAST countries with similar patient discharge data were associated with variation in hospital mortality after common surgical procedures.
The value of nursing

Cancer Patient Experience Survey 2014

National Report
The value of nursing

Key drivers analysis of the 2014 data shows that the single most important factor associated with high patient scores, in every tumour group, is the patient being given the name of a clinical nurse specialist (CNS) in charge of their care.
The context and organisation of care

- Oral chemotherapy
- Targeted therapies
- Combined chemo-radiation
- Increasing number of survivors

- Shorter hospital stays
- Site specialisation
- Policy drivers e.g. self care
- Waiting time targets
- Workforce factors
- Technology

Potential for nurse-led cancer care
Opportunities for nurse-led care

- Screening
- Diagnosis
- Treatment
- Rehab
- Follow up
- Late effects
- End of life
465% increase in nurse-led outpatient attendances

Nursingtimes.net  29.3.11
Nurse led clinics in Scotland

100 clinics surveyed, 88 responded
38% had no cover for nurse absence
20% no admin support
36% did not record statistics centrally
30% no assessment of competence recorded
55% no evaluation or audit conducted

Hutchison et al Cancer Nursing Practice, 2011, 10(9):29-35
Two main models (Corner 2003)

- Restricted delegation model
- Comprehensive advanced practitioner model

Substitution of physicians by nurses in primary care: a systematic review and meta-analysis

Nahara Anani Martínez-González¹, Sima Djalali¹, Ryan Tandjung¹, Flore Huber-Geismann¹, Stefan Markun¹, Michel Wensing¹² and Thomas Rosemann¹*
Nurses are just as effective as doctors at performing diagnostic endoscopies and delivering outpatient clinic follow-up after the procedure, say UK researchers Nursing Times 2009
ASCO predicts shortage of oncologists as demand grows

By: ALICIA AULT, Oncology Practice Digital Network
March 12, 2014
Many large European countries may be facing a future shortage of medical oncologists without realising it.

ECC 2013
Advanced Practitioner

Nurse Practitioner/Advanced Practice Nurse is a registered nurse who has acquired the expert knowledge base, complex decision-making skills and clinical competencies for expanded practice, the characteristics of which are shaped by the context and/or country in which s/he is credentialed to practice. A Master’s degree is recommended for entry level (International Council of Nurses 2008)
Differences across Europe

• EONS survey of specialist nursing 2008
• 14/32 Oncology Nursing Societies responded (44%)
  – Numerous different titles
  – Barriers to development
    • Clarity and definition of role, resources, policy / system / organisational / team support
  – Large differences in educational provision
    • 8 (57%) provided Masters degrees in cancer care (cf 4 in 2003)
    • 7 (50%) provided specialist breast cancer courses, fewer (n=5) for other tumour types
  – Recognition of specialist role in 5 (36%) countries
  – Higher salary for specialist nurses in 2 countries
• 6 RCTs + 1 before/after study
• 4 breast, 1 lung, 1 prostate, 1 ovarian cancer
• Variety of models of follow up
• No statistically sig. differences in psychological morbidity, survival or recurrence
The socioeconomic value of nursing and midwifery

A rapid systematic review of reviews

Jenny Caird, Rebecca Rees, Josephine Kavanagh, Katy Sutcliffe, Kathryn Oliver, Kelly Dickson, Jenny Woodman, Elaine Barnett-Page and James Thomas

EPPI-Centre
Social Science Research Unit
Institute of Education
University of London

EPPI-Centre report no. 1801 • January 2010

“Nurse led cancer care when compared with doctor-led care appears to be beneficial for physical, satisfaction and organisational outcomes in some types of cancer. No evidence of a difference in providers was found in terms of survival, psychosocial or resource related outcomes”
Nurse-led follow-up care for cancer patients: what is known and what is needed

Jacqueline de Leeuw • Maria Larsson

• 21 studies, 5 RCTs
• Colorectal (2) Oesophageal (1) Breast (2)
• medical safety, satisfaction, quality of life similar or slightly better in nurse-led care
More recent evidence?
More recent evidence?

Original Article

Nurse-Led Follow-Up at Home vs. Conventional Medical Outpatient Clinic Follow-Up in Patients With Incurable Upper Gastrointestinal Cancer: A Randomized Study

Madeleen J. Uitdehaag, RN, PhD, Paul G. van Putten, MD, Casper H.J. van Eijck, MD, PhD, Els M.L. Verschuuren, RN, PhD, Ate van der Gaast, MD, PhD, Chulja J. Pek, RN, MN, Carin C.D. van der Rijt, MD, PhD, Rob A. de Man, MD, PhD, Ewout W. Steyerberg, PhD, Robert J.F. Laheij, MD, PhD, Peter D. Siersema, MD, PhD, Manon C.W. Spaander, MD, PhD, and Ernst J. Kuipers, MD, PhD

Erasmus MC University Medical Center Rotterdam, The Netherlands
More recent evidence?

Efficacy of tele-nursing consultations in rehabilitation after radical prostatectomy: a randomised controlled trial study

Bente Thoft Jensen, Susanne Ammitzbøll Kristensen, Sofie Vistoft Christensen and Michael Borre
More recent evidence?

PROSPECTIV — a pilot trial of a nurse-led psychoeducational intervention delivered in primary care to prostate cancer survivors: study protocol for a randomised controlled trial

Eila Watson,1 Peter Rose,2 Emma Frith,1 Freddie Hamdy,3 David Neal,4 Christof Kastner,4 Simon Russell,4 Fiona M Walter,5 Sara Faithfull,6 Jane Wolstenholme,7 Rafael Perera,2 David Weller,8 Christine Campbell,8 Clare Wilkinson,9 Richard Neal,9 Prasanna Sooriakumaran,3 Hugh Butcher,10 Mike Matthews10
More recent evidence?

Evaluating a nurse-led survivorship care package (SurvivorCare) for bowel cancer survivors: study protocol for a randomized controlled trial

Michael Jefford\textsuperscript{1,2,3}, Sanchia Aranda\textsuperscript{1,2,3,4}, Karla Gough\textsuperscript{1}, Kerryann Lotfi-Jam\textsuperscript{1,5}, Phyllis Butow\textsuperscript{6,7}, Mei Krishnasamy\textsuperscript{1,2,3,5}, Jane Young\textsuperscript{6,8,9}, Jo Phipps-Nelson\textsuperscript{1}, Lahiru Russell\textsuperscript{1}, Dorothy King\textsuperscript{1} and Penelope Schofield\textsuperscript{1,2,3,5}
Integrated collaborative care for major depression comorbid with a poor prognosis cancer (SMaRT Oncology-3): a multicentre randomised controlled trial in patients with lung cancer

Jane Walker, Christian Holm Hansen, Paul Martin, Stefan Symeondes, Charlie Gourley, Lucy Wall, David Weller, Gordon Murray, Michael Sharpe, for the SMaRT (Symptom Management Research Trials) Oncology-3 Team

Summary

Background The management of depression in patients with poor prognosis cancers, such as lung cancer, creates specific challenges. We aimed to assess the efficacy of an integrated treatment programme for major depression in patients with lung cancer compared with usual care.

Methods Symptom Management Research Trials (SMaRT) Oncology-3 is a parallel-group, multicentre, randomised controlled trial. We enrolled patients with lung cancer and major depression from three cancer centres and their...
Impact of a novel nurse-led prechemotherapy education intervention (ChemoEd) on patient distress, symptom burden, and treatment-related information and support needs: results from a randomised, controlled trial

S. Aranda¹,²*, M. Jefford¹,²,³, P. Yates⁴, K. Gough¹, J. Seymour²,³, P. Francis³, C. Baravelli¹, S. Breen¹,² & P. Schofield¹,²

¹Department of Nursing and Supportive Care Research, Peter MacCallum Cancer Centre, Melbourne; ²Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne; ³Division of Haematology and Medical Oncology, Peter MacCallum Cancer Centre, Melbourne; ⁴School of Nursing, Queensland University of Technology, Brisbane, Australia

Received 22 April 2010; revised 20 October 2010 & revised 19 January 2011; accepted 28 January 2011
The effectiveness of a self-efficacy-enhancing intervention for Chinese patients with colorectal cancer: A randomized controlled trial with 6-month follow up

Meifen Zhang¹, Sally Wai-chi Chan²,*, Liming You¹, Yongshan Wen³, Lifen Peng⁴, Weiyan Liu⁵, Meichun Zheng⁶
Not just follow-up

A nurse-led psycho-education programme for Chinese carers of patients with colorectal cancer

Nga Fan Shum and colleagues report on a randomised controlled trial of the effectiveness of telephone support in Hong Kong
Evidence for the *safety* of nurse led care

- 40% patients did not see a hospital doctor during nurse-led follow up care (Moore et al 2002)
- 21/125 (17%) consultations with the nurse led to medical review (Wells et al 2008)
- 21/54 (39%) were referred to a doctor because of symptoms or medical problems (Verschuur et al 2009)
- Assistance from surgeon needed in 13/182 (7%) nurse consultations – 75 mins overall (Strand et al 2010)
Evidence for the safety of nurse-led care

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More evidence needed:
- Long term outcomes
- Unintended / unanticipated consequences
- Wider impact on team
Quality of life....?

• Most studies show equivocal HRQoL overall

• Lung cancer follow up (Moore et al 2002)
  – Nurse led pts less severe dyspnoea at 3 mths (p=0.03) & better emotional functioning at 12 mths (p=0.03)
  – Nurse led group more likely to die at home (p=0.04)

• HN cancer psychosocial support intervention (de Leeuw et al 2013)
  – Significant reduction in depressive symptoms at 12 months
  – Significant reduction in pain, swallowing and mouth opening at 12 months

• Colorectal cancer self-efficacy enhancing intervention (Zhang et al 2014)
  – Significant improvements in self-efficacy, symptom severity, symptom interference, anxiety and depression at 3 and 6 months
Is nurse-led care cost effective?

• In general, nurse-led appointments longer
• Lung cancer follow up (Moore et al 2002)
  – Fewer medical consultations in first 3 mths post completion of Tx (p=0.01)
  – Fewer CXRs at 3 and 6 months
  – Patients more likely to die at home (p=0.04)
• Breast cancer follow up (Koinberg et al 2004)
  – Mammography use higher in nurse-led follow up on demand
  – 21% more “contacts” in physician-led group
• Upper GI follow up (Vershuur et al 2009)
  – Costs of nurse-led visits sig. lower (p<0.001)
  – Mean hospital stay 8.9 vs 17.8 days (p=007)
• Breast cancer follow up (Kimman et al 2011)
  – Hospital follow up = more QALYs but €€€
  – Telephone f-up more cost effective
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More evidence needed on

- Societal costs e.g. Impact on carers, working lives
  Impact on primary care

...
Patient satisfaction

• Vershuur et al (2009) *BJC* 100, 70–76
  – Spouses more satisfied (p = 0.03) and could ask more questions (p=0.06)
  – Patients and spouses less likely to feel that standard follow up met their expectations (p=0.04, 0.03)

• Beaver et al (2012) *Colorectal Disease* 14, 1201–1209
  – Telephone f-up group sig. more satisfied at follow up (p= 0.029)
  – 9/10 raised concerns cf 3/7 in conventional f-up group
Patient satisfaction

- Overall satisfaction (patients and carers) significantly higher in nurse-led group
- Advice and information given
- Involvement in own care planning
- Less burdensome
- More likely to opt for nurse-led care if given a choice

Nurse-led home f-up vs medical f-up for patients with incurable gastric cancer (Uitdehaag et al 2014)
Do patients want nurse-led care?

- A survey of 263 HN patients in the UK found that 75% favoured a less intensive and more patient triggered follow-up system, and half were happy to have the specialist nurse as first port of call (Trinidade et al 2012)

Recruitment and consent to nurse-led RCTs is high
Patient satisfaction: A valid concept?

Experience

Hopes

Expectations

What are we trying to achieve?

“Well, many of these new roles are dominated by biomedical models and may not consider what added value nurse-led care may provide, and how it can contribute to organizational cultural change.”

(Faithfull & Hunt 2005 p 441)
What has been particularly good about your follow-up care?

- 63% discussed psychosocial concerns
- 42% discussed anxiety/depression
- 33% fear of recurrence
- >50% discussed family, work +/- finances

*Fig. 4. Advantages of telephone follow up (n = 35, citations = 43).*

*Telephone follow up ovarian cancer (Cox et al 2009 EJON 12, 412-417)*
The significance of a nurse-led clinic

A source of safety and security

Knowledge & practical advice

Coordination & control

Commitment & concern

“I have all the time known that the nurse has been there for me. It has never been any problem so to speak, because I know that I can call the nurse if there is anything….it’s safe and secure to have her, if something should happen”

I was more at ease with the nurse, making me more relaxed and able to talk freely.

Someone to have special contact with you who gets to know you and how you cope.

I saw the doctor when I wanted to – the time I had with him could just be short.

Usually with a doctor you only get five minutes and your mind’s all boggled with...it’s like having a negotiator between the doctors and yourself...

Wells et al (2008) JCN nurse-led on treatment review
• Purpose?
• Values?
• Outcomes?
• Balance between ‘nursing the clinic’ and ‘nursing the patient’

*Mcilfatrick et al 2006 JAN 15, 1170*

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*Which way should I go?*

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

Alice in Wonderland by Lewis Carroll
“as nurses take on more duties and responsibilities .....what, if anything, is being lost from nursing, does it matter and to whom?”

Cullum et al 2005 BMJ
‘Lost’ nursing care

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

We can’t do everything!

More substitution?  

More comprehensive nursing care?
The future is not what it used to be

Paul Valery
French critic & poet (1871 - 1945)
• The % population over 65 will rise
• from 17% in 2010 to 23% in 2035 (UK)
• % from 21% to 31% (Germany)

UN 2012; Office for National Statistics 2012
All Cancers Excluding Non-Melanoma Skin Cancer (C00-97 Excl. C44): 1975-2011
European Age-Standardised Incidence Rates per 100,000 Population, by Age, Persons, Great Britain

Please include the citation provided in our Frequently Asked Questions when reproducing this chart: http://info.cancerresearchuk.org/cancerstats/faqs/#He

Prepared by Cancer Research UK
Figure 1: Number of chronic disorders by age-group

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)

• Population cohort study of ~3500 people found that comorbidity significantly increased the odds of patients expressing a physical rehabilitation need

• Mod-severe comorbidity sig. associated with family, emotional, financial needs (Holm et al, Acta Oncologica 2014)
Figure 4: Selected comorbidities in people with four common, important disorders in the most affluent and most deprived deciles

Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study
Karen Barnett, Stewart W Mercer, Michael Norbury, Graham Watt, Sally Wyke, Bruce Guthrie
LANCET 2013

www.thelancet.com Published online May 10, 2012 DOI:10.1016/S0140-6736(12)60240-2
Cancer of the head and neck (ICD-10 C00-C14, C30-C32)
Age-standardised incidence and mortality rates by SIMD 2009 deprivation quintile, persons

Impact of deprivation on QoL

<table>
<thead>
<tr>
<th>Variable</th>
<th>Odds Ratio</th>
<th>95% CI (lower)</th>
<th>95% CI (upper)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>SIMD 5 (most affluent)</td>
<td>1.0</td>
<td>0.8</td>
<td>5.49</td>
<td>0.132</td>
</tr>
<tr>
<td>SIMD 4</td>
<td>2.09</td>
<td>0.8</td>
<td>5.49</td>
<td>0.132</td>
</tr>
<tr>
<td>SIMD 3</td>
<td>1.44</td>
<td>0.5</td>
<td>4.13</td>
<td>0.494</td>
</tr>
<tr>
<td>SIMD 2</td>
<td><strong>3.01</strong></td>
<td>1.14</td>
<td>7.92</td>
<td><strong>0.026</strong></td>
</tr>
<tr>
<td>SIMD 1 (most deprived)</td>
<td><strong>4.54</strong></td>
<td>1.61</td>
<td>12.82</td>
<td><strong>0.004</strong></td>
</tr>
<tr>
<td>Age</td>
<td>0.96</td>
<td>0.93</td>
<td>0.99</td>
<td>0.026</td>
</tr>
<tr>
<td>Feeding tube</td>
<td>No</td>
<td>1.0</td>
<td>1.58</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td><strong>3.55</strong></td>
<td>7.95</td>
<td><strong>0.002</strong></td>
</tr>
</tbody>
</table>

Cross-sectional study of 278 head and neck cancer survivors
Logistic regression – poorest scoring third on QoL measure (QLACS)
Adjusted for diagnosis, stage, gender, time since diagnosis, treatment, smoking, alcohol
Impact of deprivation and comorbidity on research participation

- 83% response from the most affluent group (SIMD 5) compared to 53% from the most deprived (SIMD 1); p<0.0001 (Wells HN study)

- 81% of RCTs published in high-impact journals excluded patients with medical comorbidities

- Older people consistently excluded from trials

  Hughes et al Age and Ageing 2013; 42: 62–69
Cancer is also changing

Data from Mistry et al 2011
Changes in the treatment of cancer

• Increasing use of targeted therapies
  – new drugs, new side effects, new costs
• Potential for more accurate diagnostic testing
  – reduction in need for adjuvant therapy?
• Changes in surgical techniques
  – less invasive, more experimental
• Advances in radiotherapy
  – more technically demanding, less toxicity
Physical side effects of treatment
Changes in appearance
Loss of self
Pain
Anxiety and depression
Fears of recurrence
Functional changes
Cognitive changes
Emotional difficulties
Ability to work
Ability to go out for a drink or meal
Need to frequently use toilet
Eating problems
Sexual problems
Financial worries
People talk to you differently
Gain of self
Physical side effects of treatment
Changes in appearance
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Pain
Anxiety and depression
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Functional changes
Cognitive changes
Emotional difficulties
Ability to work
Ability to go out for a drink or meal
Need to frequently use toilet
Eating problems
Sexual problems
Financial worries
People talk to you differently

Figure 2. The Emergent Integrated Circuit of the Cell
• 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)
http://www.nhsiq.nhs.uk/media/2534363/routes-from-diagnosis-report.pdf
Five key shifts in the approach to care and support for people living with & beyond cancer

1. Cultural shift in approach - focus on health & wellbeing
2. Holistic needs assessment, information & personalised care planning
3. Support for self-management
4. Follow up to aftercare, early recognition, preparation for consequences of treatment
5. Measuring experience and patient reported outcomes

www.ncsi.org.uk
Are nurses prepared?

- Electronic survey sent to 222 members of BAHNON in Nov 2013 & Jan 2014
- Current practice, skills and confidence

4 sections:
1. respondents’ roles, current models and views of follow up
2. views and experiences of Holistic Needs Assessment (HNA)
3. care planning and end of treatment summaries
4. structured rehabilitation support

222 sent
47 addresses invalid
1 co-author
79 responses
3 duplicates
76 responses 44% of 174

Wells & Semple 2014 EJCC
Results of BAHNON survey

- 70% agreed that nurses and allied health professionals could take on a greater role in follow-up
  - Low risk disease, prompt access to medics
- 70% conducting holistic needs assessment at some point of the cancer journey but fewer providing care plans
- >50% provided end of treatment summary, but less than 1/3 included information on treatment toxicity or late effects
Which, if any, of the following barriers prevent you from undertaking Holistic Needs Assessment (HNA) in your unit?

- Lack of time
- Lack of private space
- Lack of training on how to undertake assessment
- Lack of appropriate services to refer on to
- Other
## The subtleties of assessment

<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>
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</tr>
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</table>
Knowledge, skills and confidence in managing post-treatment issues

- Dry mouth: 3.5
- Pain: 3.0
- Taste changes: 2.9
- Fatigue: 2.8
- Smoking: 2.7
- Appearance: 2.7
- Skin problems: 2.7
- Fear of recurrence: 2.7
- Alcohol: 2.5
- Swallowing difficulties: 2.5
- Weight problems: 2.5
- Sleep: 2.4
- Physical activity: 2.3
- Anxiety & depression: 2.3
- Work related issues: 2.3
- Dental health problems: 2.2
- Lymphoedema: 2.2
- Financial issues: 2.1
- Sexual difficulties: 2.1

(Bar chart showing relative confidence levels for various post-treatment issues)
Consequences of Cancer and its Treatment Collaborative
1. Clinical Nursing practice
2. Care co-ordination
3. Proactive management of late effects/survivorship care – helping individuals make informed choices
4. Psychosocial well being
5. Identifying high risk individuals, promoting health and preventing ill health among high risk individuals and groups
6. Supporting self care, self management and enabling independence
7. Professional practice and leadership
8. Interagency and partnership working
• 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, Williams, Firnigl, MacGillivray, Lang, Coyle, Kroll* 2012 *Psycho-Oncology*

• How patients’ feedback was used to re-design a head and neck cancer service *Taylor, Tooman & Wells* 2014 *Cancer Nursing Practice*
Transforming nurse-led care after treatment

• Assess individual concerns, priorities and unmet needs more regularly as part of a holistic needs assessment
• Recognise that cancer isn’t the only problem
• Emotional, social, work and lifestyle issues are as important as physical symptoms
• Interventions to address key concerns and enhance self-management – need to be multi-dimensional
• Longevity of symptoms and knowledge of late effects
• Find ways of accessing, targeting & engaging ‘at risk’ groups
• Enabling carers, strengthening community care
• Education and support for new roles
• Further research to understand patterns and risk factors and to develop and evaluate interventions and new models of care – rigorous designs are needed
“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
THANK YOU