The Royal Marsden
NHS Foundation Trust

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Nursing Excellence in Cancer and End of Life Care

Dr. Shelley Dolan
Chief Nurse The Royal Marsden Hospital
Clinical Director, London Cancer Alliance

Objectives (1)
– A glimpse into the future – trends for healthcare and cancer care
– If you had a magic wand – what would your service look like?
– Letting go of the old and embracing the new
– New themes: new environment; therapies; partners in care; New Care Models (Vanguard); survivorship.
– Excellent care at a time of financial austerity
– Demonstrate nursing excellence and leadership

Objectives (2)
– History of nursing roles in cancer care
– The evolution of nursing roles
– The purpose of new roles – innovation
– Design, implementation and evaluation
– Nursing support roles
– Patient / family evaluation
When William Marsden designed the first cancer hospital in 1852 - very different context

He would probably have had these principles and we know he wanted free access to everyone:

"Safe, effective care and a positive patient experience"

"We need to ensure that all patient and family care is governed by these overarching principles"

However very different context of care in 2015:

- Patient autonomy
- Multiple models of care – inpatient care quickly disappearing
- New therapies that may mean life long therapy (targeted therapies)
- New technology
- New providers of care NHS and private sector models
- Nurse-led care
- Care across populations – Cancer Vanguard
- Much has changed beyond recognition and it is still evolving – so we need to stay ahead of the curve and lead the change.
The key perhaps is to be clear about the roles and innovations that we want to deliver – and then to be flexible and adaptable about the way it is delivered. Flexibility can be challenging – involves risk taking, breaking boundaries and taking people with us – and all of this is in a context of very challenging financial times.

What are some of the ingredients to plan a new or evolving service.

– Firstly not to be afraid of change – it is happening all around us so we need to be leaders of it.
– In planning service / practice role change to meet the next 3-5 years – perhaps we should consider the following:
  – What do we do that is evidence based – and what is based on custom?
  – Example - follow up
  – What could we change / do differently?
  – Care Home Vanguards

So the patients will be:

– Probably generally more informed
– May be older having more acute treatment
– Also the teenage and young people (19-24)
– Will for the majority of the time be at home
– Will be survivors of cancer care
– Will expect 24/7 specialist palliative care at home
– Does your current or future service plans meet these needs?
– What do your patients / carers think of your service – what would they change?
More ingredients for our future service / practice plans?

- What kinds of treatments will our patients be having?
- How do we influence prevention, awareness, healthy lifestyles?
- Minimally invasive surgery
- Moderate surgery with immediate reconstruction
- Intraoperative radiotherapy (brachytherapy)
- Targeted therapy
- Chemotherapy
- Intensity Modulated Radiotherapy Treatment
- Therapies to mitigate the consequences of cancer therapy
- Palliative care accessed by all, End of Life Care triggers and plans for preferred place of death
- Across the World cancer nurses are changing their roles/practice to include prevention and survivorship (NCIN 2015).

Personalised therapy

- Research into molecular pathology will mean increasingly that personalised therapy is targeted to the unique human genome that is that individual.
- Precision medicine and personalised care – a mantra for 2015 – 2020 cancer nursing.
- We need to be prepared (Calzone et al 2014)

Conventional chemotherapy

1916

1948

Medizinische Klinik
Universität Heidelberg
Ulf E. Schmitz

Cl → S → Cl

Cl → N → Cl
Future directions: molecular therapy

Personalised medicine: one size fits all?

All patients same treatment

Good response
Low toxicity (Normal dose)

No response
High toxicity (New drug)

(Lower dose?)

All patients same treatment

Low toxicity (Normal dose)

No response (New drug)

No response
High toxicity (New drug)
Future directions: personalised medicine

Here is my sequence! What should I take...?
So what is personalised care?

What do people want from their care?
What would WE want?

Definition of personalised care

- Patient centred care?
- Personalised medicine
- Placing the patient in the middle of care
- Truly personalised care is the care we as individuals would all want to receive:
- The best care: based on evidence and co-designed by the patient / family and health care professionals. Care that is not fragmented but continuous and coherent.
What do we mean by quality care: personalised care? (Professor Jessica Corner, Dr. Jocelyn Cornwell)

What do patients with cancer say they want? (2009)

- Fast access to reliable health advice
- Effective treatment delivered by trusted professionals
- Participation in decisions and respect for preferences
- Clear, comprehensible information and support for self-care
- Attention to physical and environmental needs
- Emotional support, empathy and respect
- Involvement of, and support for, family and carers
- Continuity of care and smooth transitions.

Europe Picker Institute (2009)

What do patients with cancer say they want? (2014)

The same as previously with a few additions:
- Care in the appropriate setting
- Informed discussion on health risk/benefit ratio
- Right care, right place, right time (less waiting)
- Integrated care
- Locally where possible, prepared to travel when important (UKONS 2014)
Safe and effective care with a positive patient experience

- Needs to be front and centre of every healthcare strategy
- In many healthcare settings in the UK and US led by the Chief Nurse
- Benefits and risks for nursing
- If nursing leads the quality agenda – very powerful
- After major public failings in the UK health service – Quality Agenda – an important political topic.

In every healthcare setting - critical principles of quality

- Comprehensive strategy Board to ward re-engagement and co-design of strategy with patients/ families/ citizens/ frontline staff in all areas – through to the Board.
- **How to engage with patients / carers / citizens?**
- Patient groups, Patient Experience and Quality group, Listening Post, Council of Governors, Executive Walkarounds, Frequent Feedback surveys, Friends & Family Test, national surveys.

Values and effective care conjoined
Integrated care means person centred care

“I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me.”

What is the problem?

- Increase in demand and activity
- Patient population
- High rates of organisational change
- Short term relationships
- Pressures to reduce length of stay
- Long shifts
- Reported problems with patient experience globally across healthcare settings

Patients’ experiences are a mix of the ‘what’ (T) and the ‘how’ (R)

- Respect for values, preferences, and expressed needs (R)
- Coordination and integration of care (T)
- Information, communication, and education (T+R)
- Physical comfort (T)
- Emotional support (R)
- Welcoming the involvement of family and friends (T + R)
- Transition and continuity (T)
- Access (T)
The combination of transactional (T) and relational (R) dimensions is often difficult.

Efficient and impersonal
Efficient and warm
Chaotic and rude, indifferent
Chaotic and warm

Staff engagement and care: the evidence

- Quality of staff experience precedes quality of patient experience (Maben et al 2012)
- Analysis of national staff and patient experience surveys: the two sets of experience are related (Raleigh et al 2010)
- Management and quality of HR practice linked to mortality and other quality measures (West et al 2009)

The evidence

Good staff care is an antecedent to good patient care

"Investment in staff wellbeing and ward climate is essential for the consistent delivery of high-quality care for older people in acute settings"

(Maben 2012, Int. J. Older Peoples Nursing)
What is the effect of the problem? Continued
Dr Kieran Sweeney GP, academic, patient

“The health professional does a job, and for many people this job is pretty mundane. They’re doing the same kind of thing to the same kind of people pretty well every day. So for them that activity becomes completely routine. And in some cases rather dull.

For the individual patient it’s anything but that. Every individual that comes through a hospital is apprehensive. It’s a strange place, you lie in a strange bed, you have strange sheets, you have odd tea in a plastic cup. The whole thing is vibrantly different.”

http://www.youtube.com/watch?v=--uMNY55nw4

“Mesothelioma: A patient’s journey” Sweeney, Toy and Cornwell: Bmj 2009

What is the effect of the problem?
– Withdrawal for emotional protection
– Isolation, depression and stress
– Large minority burnout
– Lowered sense of personal effectiveness
– Emotional exhaustion
– Depersonalisation of Care

Kindness suffers as the capacity for fellow feeling recedes
(Ballat and Campling 2011, Intelligent Kindness)
Kenneth Schwartz

- Died in 1995 from NSCLC aged 40.
- Noted differences between staff and levels of compassion
- Set up non profit organisation to nurture staff

**Aim of Rounds: to improve the culture of the organisation and to support staff**

- To make the unbearable bearable through small acts of kindness
- Strengthen relationships between patients and staff
- Premise was that caregivers are better able to make personal connections with patients when they have a greater insight into their own responses and feelings
- Space to do this....

**Who supports Schwartz Rounds**

- Mentioned in the Francis report as being something that can improve team building
- NHS England Business Plan published in March 2014 mentioned Schwartz as evidence based initiative to improve patient experience
- Now running in over 100 healthcare organisations across the UK
What is the Schwartz Round (format)

- Lunch is offered at the start of the round (12.30-1, round 1-2).
- Each round has a theme
- Presenting team talk for approximately 15 minutes where the story is told
- Trained Facilitators moderate the discussion
- Audience is asked to share their thoughts, ask questions, offer similar experiences.

Examples of Round themes

- Trying to help impossible circumstances
- Conflict with patient, family, colleagues
- Unrewarding situations
- Organisational events (poor CQC report etc)
- Personal and professional overlap
- The patient I will never forget

People involved

- All staff involved in the rounds
- Clinical lead
- Facilitator
- Administrator
- Steering group
Impact of Schwartz Round (UK)

- Staff confidence in handling sensitive issues
- Beliefs in the importance of empathy
- Actual empathy with patients as people
- Confidence in handling non-clinical aspects of care
- Openness to express thoughts, questions and feelings

Overall impact

- Feelings acknowledged, stress reduced
- Encourage networking and MDT working
- Contribute positively to the culture of the organisation
- Power of senior staff who express vulnerability
- Shared understanding of experience
- Different opportunity to think when not trying to problem solve

Where will our patients be?

- The mantra for today’s and tomorrow’s healthcare systems:
  - Localise where possible
  - Centralise where necessary
  - Integrated care pathways.
  - As care shifts away from hospitals on a continuum nearer to home – how will we respond to this as expert acute (secondary) care nurses?
  - How will you assist the transfer of services closer to home?
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Treatment closer to home

- 23 hour surgical stays
- Chemotherapy delivered at home or in infusion suites closer to home
- Networked radiotherapy reducing the patient’s journey time.
- Targeted therapy patient at home
- Patient initiated follow up – radically alters the face of breast outpatient clinics.
- Electronic portals to allow access and self-management (Azadmanjir et al 2015).

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Lets not be frightened of excellence

- Lets be aspirational in our planning
- The best care, delivered first time, in the best place by the best people
- Excellence does improve outcomes but also affects the experience of care
- Also important to remember that excellent care is not always more expensive than poor or average care.
- Plan care across the pathway – New Models of Care

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How can we prepare ourselves? What would new roles look like?

- Not to be frightened to change – develop personal resilience
- Develop skills that mean you are indispensable to the service – especially around leadership, change management, fast pace project delivery
- Plan to seize opportunities and actually create those opportunities – Nurses are the experts on nursing and cancer and palliative care
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The history of nursing roles in cancer care

- Staff Nurse, Sister, Matron, Clinical Nurse Specialist, Nurse Practitioner, Clinical Trials Research Nurse, Nurse Consultant.
- CNS in 1970s in breast cancer first advanced practice roles for nursing in the world
- The Nurse Consultant in cancer care first roles of its type in UK 2000.
- Clinical Academic roles
- Professor of Clinical Cancer Care

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The purpose of new cancer nursing roles

- Always to improve the care of citizens (public health, preventative care); patients; families; and the pursuit of nursing.
- Motivated by the need for continuous improvement against a challenging healthcare landscape.
- Financial challenge, ageing population, cancer care amidst greater co-morbidities.
- Ageing faculty of nursing.

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Domains of nursing in cancer care

- Prevention
  - Public health – every contact matters
  - Screening / diagnosis
  - On treatment
  - Clinical research trials
  - Open Access Follow Up
  - Self management
  - Survivorship – consequences of cancer treatment
  - Palliation
  - End of life Care
- Community
  - Clinic/hospital
  - Hospital
  - Community/home
  - Home
- Home/hospice/hospital

Primary healthcare nurses – new roles (Smolowitz et al 2014)
Community based cancer care nurses (Grimes et al 2014)
Working with older people with multiple long term conditions (Waterworth et al 2014)
Michel Angelo Petrone: The fear and pain of cancer

Michel-Angelo Petrone: I’m confused, I’m lost as to which way to turn to - who to turn to?

Evolution not revolution

- Cancer nursing roles need to evolve as the culture of healthcare changes
- More informed diverse and ageing population
- Integration of care across public health, primary care, community, secondary / tertiary care, hospices
- New roles to support nurses: apprentices, Macmillan 1:1 support roles, technical support, volunteers.
- ? Associate Nurse
Make quality, safety and innovation the backbone of the career framework

a. A curriculum at pre-registration and post-registration focused on the essential standards for the fundamentals of care expected of all nurses and then expertise in person-centred, safe and effective practice.

b. Integrate movement towards advanced and consultant nurse practice, focus on sustaining the provision of quality fundamental care, as well as, developing expertise in person-centred and whole systems approaches and the facilitation of this in others.

c. Implement work-based learning, linked with clinical supervision - a key approach to enable nurses to continue to provide the fundamentals of care as well as grow their expertise, provide quality, safe and effective care.

d. Consider approaches to the quality assurance/revalidation of nursing practice that have at their heart the essential and fundamental aspects of nursing as well as advanced and consultant nurse practice.

In the UK mandatory Nurse Revalidation begins in 2016 – an opportunity rather than a threat.

Invest further in clinical leadership and the clinical career to ensure that sufficient nursing expertise is retained in the workplace where it can directly impact on quality

- Free up the ward sister - a greater quality assurance role in relation to the provision of essential nursing care and the clinical supervision of the nursing team.
- Provide clinical supervision to ward sisters by modern matrons, and consultant nurses to enable continuity of support around their leadership and management role.
- Continue to invest in clinical leadership and the development of expertise in nursing that focuses upon improving the quality of care and reducing patient safety incidents.
- Need for skilled facilitators with the required skill-set to be as near the interface with patients as possible to enable learning in and from practice, implementation of evidence and standards into practice, individual and team effectiveness, implementation of shared values.
- Systems for systematic evaluation, learning from practice and shared governance need to be implemented at the workplace level.

Develop and promote nursing standards and evidence more extensively, integrating it into the electronic patient record

- Develop standards for the essentials of nursing care and related measures to enable quality of nursing to be judged and the impact of nursing to be articulated.
- Ensure nurses have access to relevant information in the workplace.
- Develop electronic health records that integrate nursing standards, standard terminology and data for measuring quality.
- Develop more explicit position on the number and quality of nurses required and commission further research in this area. UK NICE Safer Staffing 2014.
Position nursing expertise at higher levels of influence in commissioning and policy

- Ensure nursing expertise at all levels of governance and policy making is both visible and valued as a crucial apex for delivery of quality nursing care and innovation.
- Acknowledge and provide incentives for creativity, innovation and improvements in patient care.
- Commission more research on how quality and innovation is better spread and mainstreamed (RCN 2011-14).

EONS: Stated objectives

- Integration of
  - Research
  - Teaching
  - Service
- Improving outcomes for patients
- Improving the health of communities
- Improving the education and training of staff
- Translation of research from bench to bedside
- ..... A more compelling vision!

‘The practice of nurses, midwives and allied health professionals needs evidence to ensure that care is effective, efficient and given with intelligent kindness’

‘We need to nurture the next generation to become research savvy, to critically appraise evidence and to become research active and generate new evidence…so we can improve care, health and health outcomes’

Professor David Foster
Deputy Director of Nursing, Department of Health England
April 2013
Why?

- Research improves patient outcomes, experience and makes effective use of resource
- High-quality evidence to inform clinical decision-making
- Clinical academics are ideally placed to facilitate the adoption and spread of best practice, innovation and new technology

Objectives of the group

1. To be an expert reference group to advise, guide and support the development of the NMAHP clinical academic
2. To increase understanding and awareness of the clinical academic and build on existing structures and policy to develop a sustainable integrated and valued pathway
3. To increase the process, synergy, support and guidance for clinical academics on the pathway
4. To collate and articulate improved patient outcome and impact of the NMAHP clinical academic through research activity
5. Maximise influence within the changing healthcare and education architecture
Achieved so far

- Definition of clinical academic NMAHP adopted by NHS/Department of Health
- Published as part of toolkit:
  - Pathway of clinical academic (2012)
  - Capability framework (May 2014)
- Case Studies published by HSJ (Nov 2013)
- Consultation responses:
  - HEE CAT Pathway (November 2013)
  - Shape of Caring (September 2014)
Further information

Professor Kay Riley and Dr Debbie Carrick-Sen
Co-Chairs, AUKUH CAC Development Group

www.aukuh.org.uk/index.php/affiliate-groups/nmahps

Siobhan.Fitzpatrick@aukuh.org.uk

Whatever we do as we innovate - always have the person with cancer and their family at the centre

Thank you for listening

Shelley.dolan@rmh.nhs.uk