Realising the Potential of Haematology Nurses and Allied Health Professionals

Robens Suite, 29th Floor, Tower Wing, Guy’s Hospital

10 July 2017
Welcome to the conference

Glain Jones
Head of Nursing – Haematology
King’s College Hospital NHS Foundation Trust
Haematology & Nursing conference
The vital role of nurse-led in research in Haematology

Dr. Shelley Dolan
Chief Nurse & Executive Director of Midwifery

Kings College Hospital NHS Foundation Trust
Objectives

1. The context of Nurse-led research
2. A window into Patient and Family experience
3. Translation of research and clinical impact
4. Multidisciplinary team working in research
5. Working across boundaries and developing new models - person centred / patient led
6. Never forget the importance of the Clinical Trials research nurse and a career ladder and infrastructure
7. International collaboration and the future across KHP.
The context of nurse led research

Globally nurse led research has been traditionally focused on the role of the nurse academic in major universities internationally. The clinical academic is a much newer role in nursing and accounts in the UK for less than 0.1% of nurses (AUKUH 2014).

Since 2000 and the arrival of the first Nurse / Midwife Consultant roles there has been a renewed emphasis in building translational research capacity that is grounded in clinical practice and makes an impact on care delivery / practice / patient outcomes.

Although Nurse –led research is still evolving It is important to remember and celebrate those nurses / midwives who pioneered and contributed to our knowledge and understanding by being curious about the world around them, seeing a gap or a need and asking questions / changing practice.

Historically Nursing research has ranged across every field from epidemiology, basic science, psychology, anthropology, innovation science– their contribution has given us a social/anthropological window into the “lived experience of people in many settings.
Seminal Nurse Academic Research

- **Florence Nightingale** - Nurse Statistician (1820-1910)
- **Mary Breckinridge** – Midwifery in the Appalachian mountains (1920s)
- **Dame Jessica Corner** (1990s – current) Breathlessness; palliative care, older people with cancer
- **Jean Watson** – Authentic Human Caring (1970s)
- **Leanne Aiken** in US (1990s to current) RN Forecast; impact of nursing workforce on patient outcomes/mortality
- **Kathy Barnard** (1960s-1990s) in the US ground-breaking work on abused and neglected children
- **Jeanne Quint** in US (1960s) – experiences of women following serious illness
Person-centred, research-driven practice

Practice driven by research excellence, and research is driven by practice, service and care needs.
Ensuring equity of care provision; contribution of precision healthcare

- Right care/support – same standard
- Health and Well-being
- Care and Quality
- Funding and Efficiency

1 Leading Change, Adding Value. 2016
1. We will promote a culture where improving the population’s health is a core component of the practice of all nursing, midwifery and care staff.
2. We will increase the visibility of nursing and midwifery leadership and input in prevention.
3. We will work with individuals, families and communities to equip them to make informed choices and manage their own health.
4. We will be centred on individuals experiencing high value care.
5. We will work in partnership with individuals, their families, carers and others important to them.
6. We will actively respond to what matters most to our staff and colleagues.
7. **We will lead and drive research to evidence the impact of what we do.**
8. We will have the right education, training and development to enhance our skills, knowledge and understanding.
9. We will have the right staff in the right places and at the right time.
10. We will champion the use of technology and informatics to improve practice, address unwarranted variation and enhance outcomes.
Windows into experience

- Patients and families shaping care

Exploring patients’ experiences of a nurse-led follow-up service after critical care

This longitudinal qualitative study assessed the impact of a follow-up service to support patients following discharge from critical care
Exemplar: National Cancer Patient Experience Survey Data

- 6,500 Patients
- 15,403 comments
- Free text analysis of personal comments
- Leading to data generation with new NCPES surveys
- Revision of NCPES


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Supporting new nursing researchers

- Ambulatory transplants for patients with Myeloma, Lymphoma and Leukaemia undergoing autologous transplants.
- Action research as part of an MSc.
- Converted a bay on transplant unit for day attendance if necessary
Multi-disciplinary team working

- Cross disciplinary working
- Patient, public partnership
- Person-centred/designed research
- Social care/community care bridging the links
- Linking in with other disciplines outside nursing/medicine/NMAHPs e.g. business/demography in order to find solutions
Clinical Academic Careers: growing capacity

- Integrating nursing research and clinical practice
NIHR CAC Pathways
Supporting clinicians in research

- NIHR Clinical Academic Training Pathway
- Research nurse development
- Doctoral researchers
- Developing new researchers
- Service evaluations as a stepping stone for research
Exemplar in practice: Optimising Staffing

Workforce modelling/staffing:

- Southampton University
- RN Forecast (Aiken et al 2014; Griffiths et al 2015)
- Justification of nursing activity and roles
  Looking at impact on mortality in relation to education level of nurses and numbers of nurses
- Safety and quality data generation
All nurses: Consideration as problem-solving

You have a clinical question

• This demonstrates insight and critical thinking

What can you do to solve it?

• How will you do this?
• Methods?

Get the answer and try to problem solve it

Apply the new knowledge
Scope of nursing research

- Advanced nursing practice versus nurses at the ‘coal face’, engaging all in the questions and the possible impact.
- What will the ‘Future Nurse’ need to be? (Council of Deans)

- Encourage every clinical nurse to be curious about the “why” of practice and then to supply the tools and the leadership in practice to make a change

- Embrace and celebrate the importance of the Clinical Trials Research Nurse – ensure a career ladder, infrastructure and respect and position in the system.

- Increasingly UK Nurses enjoy collaboration internationally with colleagues in similar or very diverse settings findings ways to improve prevention, treatment and the experience of care.

Jill Demilew Consultant Midwife multidisciplinary research: perinatal mental health

Shared learning and development with colleagues across London across all disciplines providing Perinatal Mental health services.

Professor Louise Howard (Professor of Women’s Mental Health, King’s College London), Polly Sands (Specialist perinatal mental health midwife) and Sheila O’Connor (LEAP/CAN Midwife KHP; Research Midwife for SWAN study GSTT):

Well-being in pregnancy: Validating the Whooley questions and investigating what a 'yes' response means for maternity care.
The Future for Nursing & Midwifery research across KHP

• Above all excite and inspire our new graduate nurses / midwives
• Nurse from the old Norse means “to nurture” – care for our teams so they have the energy and curiosity to question
• At KCH over the next 2 years we will establish N&M innovation science units across all our wards / units.
• First doctoral support sessions for N&M across KHP – **Tuesday 27th June**.
• Wonderful opportunities – key focus for us “Mind & Body” fertile ground across the AHSC for collaboration and to make an impact.
• The future for N&M research is bright the future is **KHP**
• We held the First KHP Nursing Doctoral Research Forum.
• 22 attendees from across Kings, GSTT, SLAM & KCL
• Two presentations on:
  National research on Schwartz rounds
• KCL research on Intentional Rounding

Next Forum in October at GSTT

King’s Health Partners Nursing Doctoral Research Forum
We would like to invite you to a series of research seminars quarterly across KCH, GStT and SLaM. The idea is to provide a supportive environment for us to hear from expert and novice researchers and to share and learn together.

Venue: Kings College Hospital, Dulwich room, Denmark Hill
Tuesday June 27th 2017
17.30 – 19.30
Wine and Cheese provided
Thank you for Inviting me &
Thank you for listening
shelley.dolan@nhs.net

“You’re simply the best, thank you.”
Dr Shelley Dolan, Chief Nurse and Executive Director of Midwifery

To join the team at King’s go to careers.kch.nhs.uk

#PositivelyProud
Valuing the support and added contribution of a Clinical Nurse Specialist through a pathway / long term condition

Patient Stories...

Aplastic Anaemia

Nana Benson-Quarm
CNS Aplastic Anaemia
Department of Haematological Medicine
King’s College Hospital
Bone Marrow Failure Centre of Excellence at KHP

National Referral Centre for Aplastic Anaemia

National Centre of Excellence for MDS

National Commissioning Group (NCG) Centre for PNH

Haemopoietic Stem Cell Transplantation Programme for AA and MDS

Kings Haematology Malignancy Diagnostic Centre

Lead roles with EBMT and CIBMTR

NHS Blood and Transplant (NHSBT) HLA Epitope platelet transfusion study

National Bone Marrow Failure Unit at King’s

Rayne Institute
- Enabling Technologies
- Leukaemia and Stem Cell Biology

King’s Research Tissue Bank
* Patient Groups

* Aplastic Anaemia (AA)
* Constitutional Bone Marrow Failure Syndrome
* (CBMF)
* Myelodysplastic Syndromes (MDS)
* Paroxysmal Nocturnal Haemoglobinuria (PNH)

* Specialist patient group- thus require specialist CNS input/support
- KCH- BMF Clinical Nurse Specialist (CNS) Service Pathway

- Increasing referral for CBMF disorders and related genetic disorders from tertiary centres
- Development of genetic panels in both AA, CBMFS and MDS, now routinely used as part of diagnosis and prognosticating treatment and response
- Large clinical trials portfolio offering novel therapies
- Key aspect; close liaison, good rapport and maintain active communication, support, advice and education with tertiary centres – crucial (very importance for bridging the gap and building trust and confidence in the service both from patient/medical perspective)

- CNS co-ordinates, appointments and respective investigations
Services Framework

* Keyworker (disease specific CNS) allocated - right at point of initial referral (supported by CNS leaflet and business card)
* At initial diagnostic OPA, meeting and introduction of key worker, broad explanation of role, contact details given, coordination of subsequent investigations etc
* Actively advocates for patients
* Patients involvement in treatment decision
* Represent patients in multidisciplinary team meeting
* Holistic needs assessment (HNA) - To address acute/chronic & long term concerns/needs and plan care appropriately
* Sign post/referrals to appropriate health care professionals

* Develop, build and maintain a therapeutic relationship (crucial!)
Services Provided

Indefinite and long term monitoring and follow up.

Continual monitoring of early/late treatment related complications/concerns (Important for appropriate monitoring of disease stability/relapse and/or transformation)

Complex psychological concerns/needs as a probable consequence of living with a rare disease/chronic health and the uncertainties around that

Identify, discuss and offer clinical trials information for eligible patients

Ongoing psychological support, disease & treatment advice
Symptom advice

Co-ordinating investigations/appointments
Offer general support/advice

Patient information leaflets on various services, treatments etc.

Development of nurse led clinic for long term management on ongoing support/monitoring for stable patients
### 1st Table: 2013/14 National Cancer Survey
Analysis of results for Haematology

<table>
<thead>
<tr>
<th>Question</th>
<th>2012</th>
<th>2013</th>
<th>SLHT</th>
<th>2014</th>
<th>Nat</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q21 Patient given the name of the CNS in charge of their care</td>
<td>88%</td>
<td>92%</td>
<td>88%</td>
<td>92%</td>
<td>87%</td>
</tr>
<tr>
<td>Q22 Patient finds it easy to contact their CNS</td>
<td>69%</td>
<td>71%</td>
<td>69%</td>
<td>72%</td>
<td>75%</td>
</tr>
<tr>
<td>Q23 CNS definitely listened carefully the last time spoken to</td>
<td>84%</td>
<td>92%</td>
<td>93%</td>
<td>90%</td>
<td>92%</td>
</tr>
<tr>
<td>Q24 Get understandable answers to important questions all/most of the time</td>
<td>88%</td>
<td>97%</td>
<td>94%</td>
<td>92%</td>
<td>91%</td>
</tr>
</tbody>
</table>
Systematic review of cost effectiveness of nurse practitioners (NPs) and CNSs. Findings were consistent with NPs and CNSs deliver high quality patient care that results in high patient satisfaction and was cost effective (Donald et al; 2014).

A meta analysis on nursed managed outpatient protocols in adults with chronic conditions, cogitated a team approach of nursing, medical and other allied healthcare professionals using nurse led initiatives, combining telephone led services can have positive effects and help improve health outcomes on the outpatient management of adults with chronic conditions, providing practical alternatives to conventional care (Shaw et al, 2014).
Conclusion points:

“The quality of care and support that specialist nurses offer has been instrumental in reducing unnecessary hospital admissions and re-admissions, reducing waiting times, freeing up the consultant’s time to treat other patients, improving access to care, educating health and social care professionals and supporting patients in the community (RCN, 2014)”.


Thank You
Nana Benson-Quarm - AA/BMF CNS
nana.benson-quarm@nhs.net
King’s Health Partners
Mind and Body agenda

Dr Sean Cross
Consultant Liaison Psychiatrist
King’s College Hospital
Clinical Director Mind and Body Programme
King’s Health Partners AHSC

Haematology Nursing and AHP conference 10th July 2017
Overview

• The challenge we all face
• Mind and Body service innovations
  – Universal screening and apps
  – Psychological services
  – Non-haematology LTCs: Diabetes, COPD & Heart Failure
  – Enhancing consultation liaison psychiatry: CORE 24 & NCEPOD
  – Physical health plans
• Mind and Body educational innovations
  – Basic outreach
  – E-learning
  – Simulation training
• Haematology current and beyond
  – Elimination of Leukaemia Fund and 2017+
  – Nicky Thomas / Philip Alexander / Surabhi Chaturvedi / Gary Bridges
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Physical and Mental Health

30% with LTC have mental health problems and 46% with mental illness have at least one LTC.


- 15.4 million people have long-term conditions
- 10.2 million people have mental disorder

Long-term conditions and mental health are interlinked.
Nearly half of people with mental illness also have at least one long-term physical condition.

30% of people with long-term physical health conditions also have a mental illness.

15-20 years shorter life expectancy for someone with a severe mental illness or learning disability than for those without.
Our vision

We want to make sure that the lessons from research are used more swiftly, effectively and systematically to provide better, more joined up healthcare services for people with physical and mental health care problems.
We are now moving into phase two of the programme which focuses on coherent system wide change towards integrated mind and body approaches.
Phase Two – “Plan on a Page”

**Our Core Workstreams**

- **Primary Care**
- **Community Care**
- **M&B**
- **Secondary Care**

- Improving identification and diagnosis of mind and body needs through *screening* and meaningful sharing of data
- Developing new and enhancing existing *service infrastructure* to fully embed a mind and body approach
- **Learning and development** to upskill our workforce to be aware and practice essential skills confidently across both mind and body

**Our Core Workstreams**

- Roll out integrated assessment (based on IMPARTS and learning from existing processes) across system*
- Informatics infrastructure in place to enable web-based platform, including app
- Ongoing data analysis and linked via existing informatics work to integrate data and share with patients for clinical and research benefit*
- Embed MDT step care model across all relevant pathways and services, including new institutes*
- Strengthen service model with community and primary care services including IAPT*
- Build acute secondary care engagement*
- A&E front door streaming (as per STP priorities)**
- Liaison Psychiatry enhancement to “comprehensive” across KHP**
- Review and relaunch e-resources* and make available across system
- Informal on-the-job training and ongoing supervision from embedded specialists**
- Education curricula amended including placements**
- Face-to-face M&B training packages designed and delivered across media (inc. classroom, simulation and apprenticeships)*
  and across system

**Measure (patient, process, outcome)**

- **Patient ‘I’ statement:** I am asked about my physical and mental health wherever I am in the system
- **Patient ‘I’ statement:** My clinicians treat both my mind and body needs wherever I am in the system
- **Patient ‘I’ statement:** I feel supported to discuss my needs wherever I am in the system
- # Patient contacts include a health and wellbeing screen
- # Care pathways with embedded mind and body expertise, and providing integrated care
- # Uptake on mind and body education courses
- Mental health need is identified earlier in physical health pathways, enabling appropriate clinical care to be provided
- Improved psychological and biological outcomes, including quicker recovery times
- Staff can practice essential, reciprocal mind and body skills supporting improved clinical care
We have spoken to more than 200 patients, members of the public and staff since October and we have published a short report detailing our engagement to date, and what we have heard.

There have been some key themes raised repeatedly through these discussions, notably:

- A focus on **prevention** through **information & awareness raising** would support communities to stay well.
- **People who use services have a role** in improving the system and should **not be judged**;
- **Good listening** by health practitioners is key to people getting the best and most appropriate service.
- **Staff need time and capacity to understand** the whole system, to share and learn across teams – **education** and training is key.
- We need to consider the impact of long term or combinations of **medication** on people’s physical and mental wellbeing.
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Integrating Mental & Physical healthcare: Research, Training & Services

Integrating Mental & Physical healthcare: Research, Training & Services (IMPARTS) is an initiative funded by King's Health Partners to integrate mental and physical healthcare in research, training and clinical services at Guy's, St Thomas's and King's College Hospitals, as well as South London and Maudsley...
The IMPARTS package supports implementation of evidence-based guidelines

**Informatics**
- Routine collection of patient-reported outcomes with advice on care & referral

**Care pathways**
- Development of mental health care pathways for patients identified via screening

**Training**
- Training in mental health skills with ongoing supervision from a mental health specialist

**Self-help**
- Portfolio of bespoke self-help materials, tailored to specific physical conditions

**Research**
- Research database
- Development and evaluation of new interventions
IMPARTS: dermatology

Dermatology service wins top medical award

Posted on Friday 6 May 2016

Staff from Guy's and St Thomas' were named Dermatology Team of the Year at the prestigious BMJ Awards 2016.
Implementation

Current
- 45 clinics: King’s, Guy’s and St Thomas’ hospitals
- 17,844 individual patients screened
- 33,172 screening contacts

In progress
- 11 new clinics
- SLaM Physical Health Plan pilot

Future strategic development
- Renal
- Breathlessness
- Haematology Institute
- ED scoping exercise
Healthlocker

supported self-management

Service users

Clinicians

Carers

Researchers
Figure 1: Stepped Care Referrals for Distress in LTCs - Secondary Care Detection and Integrated Management across IAPT, Primary, and Secondary Care
Examples of tailored CBT for LTCS

Prof Rona Moss-Morris and group, King’s College London

Dr Nicky Thomas and GSTT psychologists
Embedding in pathways
• 30% of diabetes patients have depressive symptoms

• Depression is associated with worse glycaemic control, diabetes complications, increased costs and premature mortality

Fig. 2 Predicted survival curve for participants with and without depression. Solid line, not depressed; dashed line, depressed
The 3DFD model

- Liaison mental health services
- Diabetes management
- Social interventions

Primary care

Specialist care
Heart failure

30-40% of Heart Failure patients are depressed

**Figure.** Kaplan-Meier curves indicate the composite end point of death or hospitalization because of cardiovascular disease in 94 patients with heart failure (HF) with clinically significant symptoms of depression (BDI score ≥10) compared with 110 patients with HF without depression (BDI score <10). Note: P = .02 comparing patients with and without depression, based on proportional hazards models including adjustment for age, HF etiology, left ventricular ejection fraction, N-terminal pro-B-type natriuretic peptide, and antidepressant medication use. BDI indicates Beck Depression Inventory.
Health Foundation project: 3DLC
Psychosocial Pathway Development

Routine screening as if mental health is a vital sign
IMPARTS
Link up with existing psychosocial resources

Workforce Development

Psychosocial input into existing education or clinical routines (MDMs, CPDs, specialty education days, GP education, joint visits)
Formal workshops and informal phone/hallway consultations
Identify champions for “train-the-trainer” programme
Develop mental health for LTC training curriculum
Disease specific training for IAPT therapists

Direct Clinical Care

Stepped care model based on NICE
Psychotherapy, psychotropic medication, social care services
Joint visits and treatment planning
Mental health input to existing Pt groups (e.g. support group, cardiac and pulmonary rehab)
Include psychosocial component in patient education materials
Current expansion in liaison psychiatry

£249m new funding over 4 years from 2017/18 to expand liaison mental health in acute general hospitals

“The five year forward view for mental health

“By 2020/21 no acute hospital should be without all-age mental health liaison services in emergency departments and inpatient wards, and at least 50 per cent of acute hospitals should be meeting the ‘core 24’ service standard as a minimum.”
Treat as One
Bridging the gap between mental and physical healthcare in general hospitals
Clinical record sharing

Figure 7.2 Ability to share clinical records with different providers

n = 231, Subtotals: Local independent hospitals = 195; Local community hospitals = 195; Local mental health hospitals (including community mental health) = 196; Other local acute hospitals = 192; Primary care providers = 190
Figure 7.3 Discharge summary routinely copied to the relevant mental health team/named psychiatry consultant in the local mental health Trust/Health Board
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Education

- Continuing Professional Development
- CEPNs
- Postgraduate Training Schemes
- Undergraduate curriculums
# Three level scope

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<thead>
<tr>
<th>LEVEL</th>
<th>TARGET AUDIENCE</th>
<th>OUTCOMES</th>
</tr>
</thead>
</table>
| 1     | All clinical and non-clinical staff | Awareness of the risk and prevalence of physical and mental health comorbidity  
Awareness of where to find further information and support |
| 2     | Clinical staff who may provide care to patients with, or at risk of, physical and mental health comorbidities | Recognition and assessment of physical and mental health comorbidities, referral if necessary  
Ability to collaborate interprofessionally |
| 3     | Clinical staff who regularly provide care to patients with, or at risk of, physical and mental health comorbidities | Assessment, management, and treatment of physical and mental health comorbidities  
Instigate and lead interprofessional collaboration across primary/secondary care, acute/mental health Trusts, and other healthcare interfaces |
• https://www.youtube.com/watch?v=d5h28ZvXgr8
Nearly half of people with mental illness also have at least one long-term physical condition.

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Mental Health Crisis in the Emergency Department

Home and Community Settings

Emergency Department

Simulation Workshop at the Mental-Physical Interface

Perinatal Mental Health

Anticipating Behaviour that Challenges (ABC)

Managing Behaviour that Challenges in Dementia

Acute Hospital Inpatient

Mental Health Community

Working with Families and Networks

Children & Young People

Assessment & Mental State

Older Adult

Making the Challenging Clinical Decision

Emergency Response Team (ETS) In Situ

Duty Senior Nurse Training
• Video – animation
Maudsley simulation

www.maudsleysimulation.com

44 simulation courses
Focus on Mind and Body
Integrating mental health simulation into routine health-care education

Mental health simulation has an important role as an effective and engaging training modality in bridging the gap between education and clinical practice to improve mental health care. It is the educational practice of recreating clinical scenarios in safe environments using trained actors and technology, followed by debriefing to reinforce learning. Although simulation training has a rich history in medical education, its use in psychiatry and mental health disciplines remains in its infancy. Mental health simulation focuses on human factors and core skills required by health-care professionals, with the ultimate goal of improving quality of care are typically di scenarios in environments, to debrief the trainees. The use of users, and for to enhance h and collaboratively training methods the trainees help in learning about.

How we... HOW WE...

How we developed an emergency psychiatry training course for new residents using principles of high-fidelity simulation

ALEX B. THOMSON¹, SEAN CROSS², SUZIE KEY³, PETER JAYE³ & AMY C. IVERSEN⁴

¹Central and North West London NHS Foundation Trust, UK, ²South London and Maudsley NHS Foundation Trust, UK, ³Guy’s and St Thomas’ NHS Foundation Trust, UK, ⁴King’s College London, UK

Improving Interprofessional Approaches to Physical and Psychiatric Comorbidities Through Simulation

Asanga Fernando, MRCPsycha,b, Chris Attoe, BSca,*, Peter Jaye, BSc, MRCP, FCEMc, Sean Cross, MRCPsycha,c, James Pathana, Simon Wessely, MA, BM, BCh, MSc, MD, FRCP, FRCPsych, FMedsSci, FKC

¹Maudsley Simulation, South London & Maudsley NHS Foundation Trust, Lambeth Hospital, London SW9 9NT, UK
²Simulation and Interactive Learning Centre, Guy’s and St Thomas’ NHS Foundation Trust, St Thomas’ Hospital, London SE1 7EH, UK
³Institute of Psychiatry, Psychology & Neuroscience, King’s College London

Advances in Mental Health and Intellectual Disabilities

Simulation training to support healthcare professionals to meet the health needs of people with intellectual disabilities

Grégoire Billon Chris Attoe Karina Marshall-Tate Samantha Riches James Wheildon Sean Cross

Article information:

To cite this document:
Grégoire Billon Chris Attoe Karina Marshall-Tate Samantha Riches James Wheildon Sean Cross, (2016), "Simulation training to support healthcare professionals to meet the health needs of people with intellectual disabilities", Advances in Mental Health and Intellectual Disabilities, Vol. 10 Iss 5 pp. 284 - 292
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Elimination of Leukaemia Fund

Our nurses are vital in providing brilliant patient care.

What we do

Our Impact

Your Stories
Workshops

- Nicky Thomas
- Philip Alexander
- Surabhi Chaturvedi
- Gary Bridges

- Your own involvement going forward
Survivorship
living with, living beyond, living well

Michelle Kenyon
ELF Post BMT CNS
• cancer as a long term condition
  – how cancer can learn from other LTCs,...and how other LTCs can learn from cancer
• living with, living beyond, living well
  – The challenges of life after cancer treatment
• person-centred care
  – using clinical assessment tools & patient reported concerns to plan care collaboratively
• motivated self-management
  – Identify the barriers, unlock the potential
CANCER AS A LONG-TERM CONDITION

how cancer can learn from other LTCs.....
....and how LTCs can learn from cancer
59-year old male
26 years after allogeneic HSCT

- Chronic myeloid leukemia in chronic phase – Allogeneic HSCT at 37-years of age
  - conditioning with TBI, cyclophosphamide and etoposide
  - Persisting complete molecular remission since 1991
- Long-term follow-up
  - 2 years - cataract, surgical repair
  - 3 years - infertility and gonadal insufficiency (remarried)
  - 6 years - osteopenia (osteodensitometry)
- Over the years, cardiovascular risk factors
  - Overweight (BMI 27 kg/m2)
  - Dyslipidemia, arterial hypertension
  - No physical activity
- 18 and 20 years, basal cell carcinoma, complete excision
- 24 years, myocardial infarction
59-year old male
26 years after allogeneic HSCT

Chronic myeloid leukemia in chronic phase – Allogeneic HSCT at 37-years of age
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• 18 and 20 years, basal cell carcinoma

• 24 years, myocardial infarction

Potentially preventable illness
Health promotion opportunity
Approximately one in four – that’s 500,000

- of those who have been diagnosed in the UK with cancer at some point in their lives are facing poor health or disability after treatment
- many of these problems can persist for at least 10 years after treatment and can be significantly worse than those experienced by people without cancer

One in four people – that’s 15 million

- living with a long term condition
- spending a large amount of their own time managing their care and support
- people with long term conditions including those who have had cancer experience both physical and mental effects

**Macmillan Cancer Support (2013) Throwing light on the consequences of cancer and its treatment**
People with LTCs are intensive users of health and social care services, including community services, urgent and emergency care and acute services.

**Common LTC’s**
- Coronary heart disease
- Heart failure
- Stroke
- Hypertension
- Diabetes
- COPD
- Epilepsy
- Cancer
- Mental health conditions
- Asthma

*(DoH 2008)*
cancer as an LTC....

Specific issues for patients with cancer that would benefit from a holistic, LTC approach

• 15 months after diagnosis people with cancer had:
  – 60% more A&E attendances
  – 97% more emergency admissions
  – 50% more primary care contacts vs population of the same age/gender
  – 64% of people living with cancer have practical or personal support needs
  – 78% have emotional support needs
  
  (Nuffield Trust 2014)

• the majority (75%) of which say that these needs are caused by their cancer or cancer treatment

• many do not get the support they need to live as well as possible in their homes

• of those who do receive social care support, more people receive this 18 months after cancer diagnosis

• social care use for those with cancer < for those with other chronic diseases.

• we have to adapt and evolve our approaches to meet the needs of the future

(Five Year Forward View, DoH 2016)
LIVING WITH, LIVING BEYOND, LIVING WELL

the challenges of life after cancer treatment
Unmet needs of survivors

- **one in three** cancer survivors experience moderate to severe unmet needs at the end of treatment
- for **60%** of people, needs not improved six months after treatment (1)
- people with cancer experience **persistent long-term problems**
- even those with no other long-term conditions have **poorer quality of life** scores when compared to the general population (2)


lost in transition

£5.3 billion lost to business pa

92% lose income

40% QoL impact

33% future and health worries

20% psychosocial difficulties
Cancer – the main concerns

Clinical concerns
• chronic fatigue
• sexual difficulties
• mental health problems
• pain
• urinary and gastrointestinal problems
• lymphoedema (persistent tissue swelling caused by fluid retention)

Holistic concerns
1. Worry, fear or anxiety
2. Tiredness / exhaustion or fatigue
3. Sleep problems / nightmares
4. Pain
5. Eating or appetite
6. Anger or frustration
7. Getting around (walking)
8. Memory or concentration
9. Hot flushes / sweating
10. Sore or dry mouth

(HNA data - Macmillan 2015)
Concerns are important for well-being

- more concerns people (with cancer) have the more distressed they feel

- it can be difficult for people to discuss what’s worrying them….

.....or for healthcare professionals to pick these concerns up
PERSON-CENTRED CARE

using clinical assessment tools & patient reported concerns to plan care collaboratively
Managing cancer as an LTC

• Every patient receives a recovery package
  – holistic needs assessment
  – treatment summary
  – health and wellbeing event
  – holistic cancer care reviews in primary care

• Managing consequences of treatment appropriately, in particular:
  – Lymphoedema, pelvic radiation disease, sexual dysfunction, psychological support, pain, fatigue management

• Patients identified suitable for supported self management follow up:
  – breast, colorectal, prostate and scope for others........

Personalised, person centred care which engages with the individual, understands their goals and the support they have from carers and the community they live in is vital to have a sustainable NHS
Implementation challenges of LTFU: ‘Mind & Body’ approach

recovery package
- Holistic Needs Assessment (HNA) & Care Planning
- Treatment Summary

late-effects surveillance/prevention
- Second malignancy screening
- Treatment consequences
  - eg organ damage, endocrine dysfunction, infection/immunisation, sexual issues, psychosocial problems
- Health promotion opportunities
  - eg weight management, smoking cessation, exercise
Clinical and holistic assessment
Clinical and holistic assessment
Holistic Needs Assessment (HNA) and Care Planning

- identifies unmet needs, informs consultation
- 5 domains
  - practical, family, emotional, spiritual, physical
- needs discussed, care/ action plan developed and agreed
  - information and sign-posting
  - health promotion (diet, exercise, smoking, alcohol)
  - referrals (financial, nutrition, physio, counselling, specialist services)

- patient input to care plan empowers patient and enables self-management
Treatment summary

• Reports annual clinical assessment and review
  • based on international guidance for screening (Majhail 2012)
  • proposed actions discussed and agreed with patient
  • copied to GP, referring physician, patient

• Informs patient and GP (and other stakeholders) of care and treatment received
  • ‘red flag’ signs for relapse or late effects
  • monitoring requirements
  • key worker contact details (queries or direct referral)

• GP uses information for ‘Cancer Care Review’
Recovery package in LTFU

n=378 new patients (204m, 174f) mean 53y (range 19-75)
time post tx 6.6 years (range 1 – 24 years)
cGvHD 32 patients (4 extensive)
donor source: VUD (57%) matched sib (37%) haplo/ cord (6%)
>600 care plans and TS (3 years)
Range of concerns:

- Wound care
- Changes in taste
- Laundry/housework
- Nausea or vomiting
- Hot flushes
- Bathing or dressing
- Loss of meaning or purpose in life
- Sore or dry mouth
- Preparing food
- Caring responsibilities
- Constipation or diarrhoea
- Relationship with children
- Moving around or walking
- Indigestion
- Work or education
- Breathlessness
- Changes in weight
- Dry, itchy or sore skin
- Housing or finances
- Anger, frustration or guilt
- Memory or concentration
- Worry, fear or anxiety
- Fatigue
Top 10 concerns

<table>
<thead>
<tr>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tingling in hands or feet</td>
<td>Moving around or walking</td>
</tr>
<tr>
<td>Housing or finances</td>
<td>Breathlessness</td>
</tr>
<tr>
<td>Other medical condition</td>
<td>Sadness or depression</td>
</tr>
<tr>
<td>Anger, frustration or guilt</td>
<td>Other medical condition</td>
</tr>
<tr>
<td>Pain</td>
<td>Dry, itchy or sore skin</td>
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<tr>
<td>Memory or concentration</td>
<td>Memory or concentration</td>
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<tr>
<td>Sexual concerns</td>
<td>Changes in weight</td>
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<tr>
<td>Worry, fear or anxiety</td>
<td>Sleep problems</td>
</tr>
<tr>
<td>Sleep problems</td>
<td>Worry, fear or anxiety</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Fatigue</td>
</tr>
</tbody>
</table>
Range of interventions

- Patient did not want to explore this concern...
- Dietitian Referral
- Psychologist referral
- Signposted to Financial Advise Service
- Urology referral
- Gynaecology referral
- Physiotherapy referral
- Counselling Referral
- Medication changed
- Other referral
- Information given
- Advised to see GP
- Advised to increase physical activity levels
- Discussed concern, general advice given
- Medication reviewed
Addressing concerns – HNA prompt sheets

- LCA HNA Breathlessness Prompt Tool March 2016
- LCA HNA Constipation Prompt Tool March 2016
- LCA HNA Diarrhoea Prompt Tool March 2016
- LCA HNA Distress Thermometer Fact Sheet March 2016
- LCA HNA Fatigue Prompt Tool January 2016
- LCA HNA Insomnia Prompt Tool March 2016
- LCA HNA Memory and Concentration Prompt Tool March 2016
- LCA HNA Pain and Pain Control January 2016
- LCA HNA Physical Activity Prompt Tool January 2016
- LCA HNA Sexual Consequences for Men Prompt Tool March 2016
- LCA HNA Sexual Consequences for Women Prompt Tool March 2016
- LCA HNA Weight Gain Prompt Tool January 2016
- LCA HNA Worry and Fear Prompt Tool March 2016
Cancer and work

- Patients benefit from **early** support considering work and education options *(NCSI 2013)*

- Return to work is associated with
  - higher self-reported general health
  - improved well-being
  - good quality of life

- Work is extremely important to survivors and has health benefits

- 54% of patients in paid work 1-3 years post transplant vs 69% for all cancers combined *(Anthony Nolan 2015)*
Employment rates

- 60% working
- 53% paid employment
- Sharp fall in employment >45y = target for vocational rehab interventions
good performance status
– report low distress levels
– few concerns

• Proportion working survivors declines with age notably from age 44
• Appropriate group to target return to work interventions
• Interventions addressing return to work issues benefit individuals and society
  – Volunteer work, CV development
  – Phased return (fatigue, concentration)
  – Flexible working/home based office days
• Employed individuals less costly for the state and consume less health and social care than non-working counterparts
MOTIVATED SELF-MANAGEMENT

identify the barriers, unlock the potential
tackle behaviour = improve health = reduce LTCs

- weight management and nutrition
- exercise
- alcohol
- smoking
- work and education
- relationships

Reinforce public health messages

- 5-a-day
- alcohol units
- smoking cessation
- exercise
  - at least 150 minutes of moderate aerobic activity pw
  - strength exercises in two or more days/ pw
Making Every Contact Count (MECC)

Reversible behavioural risk factors for irreversible long-term conditions

- Tobacco
- Hypertension
- Alcohol
- Obesity
- Physical inactivity

Making every contact count (MECC) is an **approach to behaviour change** that utilises the millions of day to day interactions we have to encourage changes in behaviour

- Deliver healthy lifestyle messages
- Encourage people to change behaviour
- Direct them to local services that can help them

http://www.makingeverycontactcount.co.uk

An Academic Health Sciences Centre for London

Pioneering better health for all
brief interventions

• oral discussion, negotiation or encouragement, with or without written or other support or follow-up

• may also involve
  – a referral for further interventions such as smoking cessation clinic
  – directing people to other options ie have you thought about trying ….
  – more intensive support such as counselling or therapy

• brief interventions
  – can be delivered by anyone who is trained in the necessary skills and knowledge
  – are often carried out when the opportunity arises, typically taking no more than a few minutes for basic advice

• person-centred
non-adherence

Tips for improving adherence

- Record an accurate and current list of medications (prescribed and OTC)
- Explore barriers to adherence
- Explain the aims or benefits of medication
- Explore the patients health beliefs and their understanding of:
  - their illness
  - the role of medication(s)
  - potential risks of non-adherence
  - side effects
- Explore their knowledge and provide verbal and written information
- Identify whether prompts are needed
  - The patient intends to take medication but regularly forgets
  - Prompts have been shown to improve adherence with sustained impact

Failure to take the prescribed medication at prescribed time and/or at the prescribed dose

£500m per year is lost due to patients not taking medication properly

- One in 5 do not take all their prescribed medication
- Many forget
- ‘if you don’t feel ill, why take them?’
- ¼ fear side-effects
- Some throw them away
Summary

Recovery package can provide a framework to address a significant holistic gap not reliably met by routine care

LTFU clinic (using HNA & proforma based assessment)

- empowers patients to report concerns
- creates opportunity
  - discussion
  - information giving
  - health counselling/brief interventions
  - promotion of healthy lifestyles and health messages

- Potential to apply format to other groups and those with other long term conditions
Thank you
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