Final Report
Knowledge Exchange Seminar –
9th April 2014, Cicely Saunders Institute

Programme

9:15-09:30: COFFEE AND REGISTRATION

09:30-09:45 INTRODUCTION (Professor Rob George, Guy’s and St Thomas’ Foundation Trust)

09:45-10:50 PRESENTATIONS AND QUESTIONS

1. “Delivering integrated care in the Community” (Kate Heaps, Greenwich & Bexley Community Hospice)

2. “Implementing Outcomes in Practice” (Susanne de Wolf & Dr Simon Etkind, CSI)

3. PhD Thesis: “The last months of living: an ethnographic study of the trajectories of illness and care of patients with advanced cancer in Greece” (Dr Despina Anagnostou, CSI)

4. “Development and validation of a myeloma-specific quality of life questionnaire – the MyPOS” (Christina Ramsenthaler, CSI)

5. “Namaste in Care Homes” (Min Stacpoole, St Christopher’s Hospice)

11:15–11:30 COFFEE BREAK

11:30–12:15 DISCUSSION GROUPS

1. New models for community palliative care
2. Ensuring outcome measurements work in practice
3. Understanding families; the locus of decision making and the locus of care
4. Psychometric properties of an outcome measurement
5. Interventions for people with dementia in care homes

12:15-12:30 SUMMARY (Dr Fliss Murtagh, CSI)
**Introduction**
Professor Rob George, Consultant Physician in Palliative Care, welcomed all contributors and attendees to the seminar and encouraged all present to actively take part.

The seminar was well-attended by over 50 people from both the Cicely Saunders Institute and external organisations.

**Presentations**
1. Delivering integrated care in the Community
   Kate Heaps, Greenwich & Bexley Community Hospice

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**Background**
228,000 population, 1,696 deaths in 2011
Deprivation high – life expectancy 9 year differential (men) and 7 years (women)
SE London Marie Curie Delivering Choice Programme – 2007-2010
  - 63% of deaths in hospital
  - 18-19% at home
  - 10-11% in a care home
  - 7% hospice

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**First Steps**
- Specialist Palliative Care fully integrated – investment in 24 hour service
- Investment in advance care planning
- Investment in better end of life care in care homes
- Discharge Planning post
- District Nurse training
1st round of commissioning

- Prime Contractor Model
- Negotiated KPIs – hospital deaths (with shared incentives)
- All parties responsible for the success of the partnership
- Support one another to reach common goal
- Working together for patients

Activity and Outcomes

May 2011—December 2013

- Total Referrals – 1,171
- Total Deaths - 906
- Average Duration of Care - 127 days
- Total Number of People Eligible for “Fast Track” Continuing Care* - 512
- Proportion of Non Cancer Activity – 38%
- 60% of people now have an ACP
- Increased access from BAME community
Outcomes (March – December 2013)

Outcomes (2)
- Increase in home and hospice deaths and a reduction in hospital admissions, length of stay and deaths.
- Year 1 - average length of stay (Hospice IPU) ↓8 days, ↑ admissions
- Year 2 - average length of stay ↑12 days
- VOICES and SKIPP introduced

Other Developments
- Exploring opportunities to extend GCP to meet personal care needs of people outside of CC fast track criteria
- Greenwich CCG pilot site for PHC budgets
- Befriending service and volunteered Advance Care Planning Support provided
- Nurse Consultant Post – working across Hospital and Hospice
- Joint training and reflective sessions

Summary
- 3 organisations working together (with potential for more)
- Seamless care (24 hour telephone number)
- Opportunity to develop things outside of the core service specification and to adapt model to changing needs
- Governance structure has enabled improvements outside of this service
- Well valued by patients and carers
2. Implementing Outcomes in Practice
Susanne de Wolf and Dr Simon Etkind, CSI

Introduction – Why do we have to measure outcome in clinical practice

- Commissioning in palliative care may soon be based on outcomes data and services are being mandated to use outcome measures (Hughes-Hallett et al 2011).
- “To benchmark and measure outcomes in palliative care. Participation in PCOC enables palliative care service providers to improve practice and meet the Standards for Providing Quality Palliative Care for all Australians.”

Research questions

1. How are patient centred outcome measures (PCOMs) used in palliative care, including the methods of capture and feedback of outcomes data?

2. What are the effect(s) of capture and feedback of patient centred outcome measures on processes and outcomes of care?
Methods

- Systematic review of the literature
  - Database search, reference/citation search, gray literature, contacted experts

- Level 1 analysis: Which outcome measures used, method of data capture.

- Level 2 analysis: How was data captured and transferred, acceptability & feasibility, what was the impact of POCMs implementation on processes and outcomes of care.

Literature review flowchart

Results - Level 1

Settings in which POCMs were used

- Palliative
- Oncology

Study design

- Observational
- Interventional
- Pilot

Strength of evidence

- Strength of evidence ++
- Strength of evidence +++

POCMs feedback alters recognition of symptoms in palliative care populations

POCMs feedback facilitates discussion of HRQOL and increases understanding of patients' and professional perspective of disease

POCMs feedback empowers professionals to act on identified need

Level 2 - Effects on processes of care

Processes of Care

- Symptom identification
- Interpersonal communication
- Actions based on symptom reporting

Strength of evidence

- Strength of evidence ++
- Strength of evidence +++
Level 2 – Effects on care outcomes

<table>
<thead>
<tr>
<th>Healthcare outcomes</th>
<th>Emotional/Psychological Quality of life</th>
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<tbody>
<tr>
<td></td>
<td>Positive affect, patient distress (4/12 studies)</td>
</tr>
<tr>
<td></td>
<td>Strength of evidence: ++</td>
</tr>
<tr>
<td>Symptom Burden</td>
<td>No effect on symptom burden</td>
</tr>
<tr>
<td></td>
<td>Strength of evidence: ++</td>
</tr>
<tr>
<td>Overall Quality of life</td>
<td>No effect on overall health related quality of life</td>
</tr>
<tr>
<td></td>
<td>Strength of evidence: +++</td>
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Scope of evidence

- Evidence is concentrated in outpatient oncology.
  - Doesn't reflect the variety of areas in which PCOMs are used in palliative care
  - Doesn't reflect the population at need of palliative care

- Broader evidence is needed, particularly:
  - Evidence on feedback of PCOMs to multi-disciplinary teams
  - Evidence in the use of PCOMs in non-oncology populations
  - Evidence in the use of clinically oriented outcome measures such as ESAS and POS.

The Outcome Assessment and Complexity Collaborative (OACC)

OACC implementation begins

- All staff receive training in outcome measurement

Relationship building (CF) and clinical champions selected

Outcome measures are collected in services

- Outcome data on individual patients feed back to teams

Teams use outcome data to make decisions on patient care

- Collected outcome data is fed back to teams (6-monthly reports)

Teams use outcome data to trigger organisational change (if appropriate)


- Preparation
  - Staff reactions to change, the general view of practice changes, measurement, measurement forms, change management training

- Implementation
  - Patient assessment, Staff reactions to change, the general view of practice changes, measurement, measurement forms, change management training
OACC – implementing outcome measures – how? (practical steps)

- We are using the same outcome measures across sites
- We are listening to each member of the team throughout the whole implementation phase
- We are learning from the experiences of Australia

OACC – Feedback: a practical example

|   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
|   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| T1 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| T2 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |

Individual patient level
Graph or table or lines? SPLAT diagrams

Feedback

- Which graph / numbers / tables do you prefer?
- When would you like to receive feedback?
- How would you like to receive feedback?
- Identification of teaching
- Involving the whole team (Auxiliary to Consultant)
From practice to research and back

- The 2 year experience will show us the degree of improvement in care and quality of life in our palliative care population
- The implementation will inform national role out strategy of outcome measurement
- Mixed method research in order to understand the process and clarify its feasibility

Acknowledgement

- Thank you
- Charity Guy’s and STH
- OACC collaborating centres
3. PhD Thesis: The last months of living: an ethnographic study of the trajectories of illness and care of patients with advanced cancer in Greece
Dr Despina Anagnostou, CSI

Outline of the presentation

- Greek context - context of the study
- Aims-methods
- Findings: Longitudinal perspectives of goals and decision making
- Mind orientation over time for patients

End-of-life care culture in Greece

- The taboo of death and dying
- No palliative care services yet
- No home care services (a service is just starting in Athens)
- Active treatment – late stages of disease
- High hospital death rate
- Medical centred care (not patient centred)
Aims

• To explore the nature of care and the experience of care and illness of patients with advanced cancer in Greece.
• To understand the process of the decision making over time, in relation to treatment/care choices, place of care and death.
• To explore the preferences/choices for place of death of patients with advanced cancer in Greece as they developed over time.

Sample

Ninety participants (13 patients, 35 family members and 42 health professionals) followed over 18 months until patient death

Patients with advanced cancer: 8 men, 7 women, age range: 28-75
• Varied diagnoses: breast cancer, lung cancer, colon cancer
• Period of time spend data collecting: 1 month to 7 months

Methods

Ethnography - longitudinal qualitative study

Participant observation
• 600 hours with patients and families
• 230 hours with nurses and doctors

Interviews (semi-structured and discussions)
• Total 75 hours

Documents (medical records, ward communication notes)
• Of all 13 patients, on every admission

Data analysis
Thematic analysis and case study analysis

Trajectories of goals; families, patients and health professionals’ decision making over time

• Physicians and families were the main decision makers of the patient’s care regardless of disease severity.
• Factors influencing the changes of decision-making:
  • the locus of decision making within the family and family’s beliefs;
  • the patient’s role in the family;
  • the illness progress
  • physicians attitudes towards death, dying and end of life care.
• Perspectives varied between the three groups of participants from stage to stage
Physicians’ decision making

Physicians focused on cure and prolonging life until the late stages in the illness trajectory. When patients did not respond to treatment, they interfaced their efforts, allowing little opportunity for the transition to the palliative phase.

‘Because she does not respond/to treatment, I want to try even harder. I will try everything I can to keep her alive; am not done yet.’ (Di Donu, oncology consultant)

Families’ decision making

Families’ decision making was influenced by both physicians and patients. Their decisions aimed at supporting choices towards cure and preserving the relationship with their loved ones. However, the more the illness progressed, the more they shifted towards meeting patient’s needs and fulfilling their wishes.

‘I fight so hard for him; the disease, to keep him going but I am getting confused now. He might not make it and he really wants to go back to the village he cannot suffer anymore.’ (Filibet’s spouse)

Patients’ decision making

Patients focused more on the relationship with their loved ones, and thus their decisions were supportive of their families’ wishes. Patients’ wishes to refer to their symptom burden increased with the condition’s deterioration, alongside their suffering and the desire to keep their family close. Near the end, they sought for preparing to die and performed dying rituals.

Sotiris told his family today that he wanted no more treatment, but agreed to continue when they persisted. He said though that when the time comes, he would want to die back home in Chatinos. (Sotiris; 15 days before death)
Patient’s mindset orientation over time

Patients focused more on the relationship with the loved ones. The more they deteriorated, the more they prioritized relationships
• ‘Attachment security at the end of life’ (Rodin 2009)
• Enhancement of patient integrity of identity (Lawton 2000)

Dying phase was initiated and lead by patients who fought to secure space and time for preparation (dying rituals)

Transition points expressed by patient’s decisions over the last 7 days of life

7 days before
- Patient asks for a respite family to visit him in the hospital,
- Suggesting specific names
- Insists to be transferred near a window to see the sun.
- He sings familiar songs facing the sun.
- He asks for a family meeting and gives his children his wishes and about his individuality.
- He asks for the right to switch off and remain quiet.

3 days before
- He asks for more treatment and asks to go home, back in the mountains. – Doctors refused.

1 day before
- He asks for the physician to visit him in the hospital.

6 hours before
- He asks for the physician to visit him in the hospital.

3 hours before
- He asks for the physician to visit him in the hospital.

1 hour before
- He asks for the physician to visit him in the hospital.

Patient orientation of preferences and priorities overtime as a new aspect for palliative care

(First figure adapted from Lynn and Adamsen, 2005)

Discussion points

Patient orientation overtime as an important element of understanding response shift and quality of life

Patient orientation of goals might have a role in patient reported outcomes? (outcome against the goal)

Patient orientation of goals might help us identify prospectively transition points in their trajectory. Helpful to plan for care?
What is next?

References


4. Development and validation of a myeloma-specific quality of life questionnaire - the MyPOS
Christina Ramsenthaler, CSI

Overview:
1. Background
2. Aims of the research
3. Development and validation of the MyPOS
   a) Qualitative interview and focus groups with patients & health care professionals
   b) Cognitive interviews/pre-testing
   c) Psychometric validation
4. Conclusions and next steps

Questionnaire development and validation
- Measurement is central to clinical practice
- Basis of diagnosis, prognosis, evaluation of medical interventions
- Outcome:
  - Change in a patient's health over time
  - "The change in a patient's current and future health status that can be attributed to preceding healthcare" (Donabedian 1966)
  - What ultimately affects the person, i.e. reduction in symptom distress, better quality of life (QoL)
- Choose measurement instrument which you can trust
Phase 1: Qualitative interviews and focus groups - Methods

- Three types of qualitative data collection:
  1. 20 in-depth interviews to elicit model of QOL
  2. 20 semi-structured interviews to explore views on existing QOL questionnaires
  3. Focus groups: 2 with patients (=7, >4) and 1 with clinical staff (=5) for exploration of desired utility for use in clinical practice
- Recruiting: In- and outpatient settings at King’s College Hospital, Guy’s and St Thomas’ Hospital and St Christopher’s Hospice
- Sampling: purposive sampling by gender, age (>/= 65 years), ECOG performance status, disease phase
- Content analysis

Quality of life in multiple myeloma

- Well being, multi-dimensional
- Myeloma patients report low physical, psychological and social functioning (Ghate et al. 2001, Nkansah et al. 2004, Upadhyay et al. 2005) and have unmet supportive care needs (Nkansah et al. 2001)
- People with myeloma may suffer more different symptoms and problems than in other haematological cancers (Janssen et al. 2000)
- QOL assessment should become part of routine care (Hemmer et al. 2005)
- Routine QOL assessment in clinical practice can help screen for unmet needs, facilitate communication and prioritise problems (Hemmer & Car 2001)
- Existing QOL questionnaires are predominantly designed for use in research (Nkansah et al. 2002)

Study Aims

- To develop and validate a questionnaire to assess the quality of life of people with multiple myeloma which is suitable for use in clinical practice.
- To describe the quality of life of people with multiple myeloma.

Overview of the study

- Phase 1: Literature review
  - Identifies and evaluates existing QOL questionnaires

- Phase 2: Qualitative interviews and focus groups
  - Identifies issues important to QOL and builds conceptual model

- Phase 3: Design questionnaire and carry out ‘pre-test’
  - Constructs new questionnaire and test it using interviews

- Phase 4: Questionnaire survey and validation
  - Multi-centre questionnaire survey to measure QOL, validate new questionnaire
Phase 1 Results: What issues matter to QOL?

- Activity & Performance
- Sleep and Energy
- Recreation and leisure
- Relationships and social functioning
- Coping strategies

"It's what I use to do in my head, the mind and the emotions, like thinking about it, and that's what I do when I'm stuck in the middle of things."

"It's the ability to know what you want to do, and to be able to do it."}

Phase 1: Do symptoms affect QOL?

- Symptoms affect QOL if they have an impact on physical function and being able to do things that people want to do.

"The quality of life, it's just having the best possible... you can't be doing anything, you don't have your quality of life going down to you can't do anything, and it was there... it's a shame. I can't do anything with the child, I can't go out with my friends.

"The point being that if you're on your feet and your health is good, it's easier to have a good quality of life because I can't harden down on my fingers and get in and out of bed easily and do things when I want to, you know, do what you need to do.

Phase 1: Importance of emotional wellbeing

- Depression and anxiety
- Coping strategies
- Family and friends
- Support from family and friends
- Coping strategies

"It's like when I was doing exercises and doing yoga and thinking about it, and then I was doing yoga and thinking about it, and then I was doing yoga and thinking about it, and then I was doing yoga and thinking about it.

"When I came out of surgery, I was very happy and it was going to be okay."

"I would like to go back to my normal life, but I wouldn't do anything like that anymore. I wouldn't take any chances."
What did participants tell us about existing questionnaires?

- Most important items: mobility, pain, care-related
- Length: shorter generally preferred
- Time frame: 3 days not long enough, one week generally preferred

Doctor's and nurse's views:
- Screen/flag problems unable to uncover in clinical consultation
- Facilitate discussion of embarrassing issues such as sexual function
- Comparison of QOL compared to when treatment started
- Focus the goals of care and tailor treatment

Summary: What have we learned about QOL tools for use in clinical practice?

- Questionnaire should cover issues most important to QOL
  - Emotional status, activity, participation, health services, other external factors
- Questions about symptoms should ask their effect on function, rather than just their frequency or severity:
  - “How often do you have pain?” VS “How much does your pain affect you?”
- Should include questions about the most clinically relevant issues
  - Anxiety, depression, pain, fatigue
- Should include questions that are hard to ask in routine practice
  - Sexual function, fear of dying
- Should be short and easy to read
  - 2-3 items A4 maximum

Phase 2: Developing & Pre-Testing the Myeloma-specific Patient Outcome Scale (MyPOS)

- Used findings to develop MyPOS questionnaire
- Carried out ‘cognitive interviewing’ of the MyPOS:
  - Small sample of patients (n=12)
  - Allowed refinement of questions
  - Face validity, Questions easy to understand, Questions cover all issues important to QOL?

  \[ \Rightarrow \] Phase III - Large cross-sectional survey of 380 patients with myeloma
  - To check whether the questions work as intended

Phase 3: QOL Survey

- 13 sites across England
- National sample

18
**Phase 3: Psychometric testing of the MyPOS (n=380)**

**Reliability:**
- Internal consistency: Cronbach's α = 0.89
- Test-retest reliability: 1 week, n=30, r=0.912, p<0.001

**Acceptability:** 7 minutes completion time, minimum missing data

**Interpretability:** Easy to complete, Ceiling effects on items: Discomfort, Nausea, Vomiting, standard of care and skills in doctors/nurses. Care and respect from doctors/nurses. Enough information about illness

**Validity:**
- Content/face validity: MyPOS captures symptoms, issues and problems important to QoL
- Structural validity: Exploratory factor analysis, 3 subscales
  - Functioning & Symptoms
  - Emotional problems and coping with illness
  - Health care support factors

**Validity:**

- **Known-group comparisons:**
  - MyPOS Function subscale discriminates between high and low ECOG performance status (F=28.83, p<0.001)
  - Total MyPOS score discriminates between disease stages (newly diagnosed, stable, relapsed/progressive) (F=11.89, p<0.001)
  - Total MyPOS score discriminates between patients on treatment and off treatment (F=14.15, p<0.001)

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**Conclusion and further steps**

- The MyPOS aids the capture of quality of life relevant for patients with multiple myeloma
- High levels of fatigue and health status
- Problem solving:
  - Physical function
  - Role and social function
  - Sexual function

**The MyCare study – Longitudinal quality of life in multiple myeloma**

1. What are the different trajectories of symptoms, QoL, and associated issues/concerns in myeloma?
2. What are the subgroups of QoL in myeloma and who is at risk of developing a poor outcome (mQoL and co)?
3. What items can be used for self-monitoring of QoL and how would patients like a system of self-monitoring symptoms and QoL to look like?
Thank you

We would like to thank all participants who have volunteered their time and shared their views on quality of life in the interviews or by filling in the questionnaires.
We also thank the nurses and doctors for their support.
Thank you to Myeloma UK for funding the study.

This work is supported by a Health Services Research Grant awarded by Myeloma UK.

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Literature


Follow us on Twitter @csl_kcl www.csl.kcl.ac.uk
5. Namaste in Care Homes
Min Stacpoole, St Christopher’s Hospice

Implementing the Namaste Care programme for people with advanced dementia at the end of their lives: an action research study in six care homes

Min Stacpoole RN  BSc
Nurse Researcher for palliative care for people with dementia
Care Home Project Team, St Christopher’s Hospice
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Other Authors

• Dr Amanda Thompsell, South London and Maudsley NHS Foundation Trust,
• Dr Jo Hockley, Care Home Project Team, St Christopher’s Hospice, London, UK,
• Professor Joyce Simard www.namastecare.com
• Professor Ladislav Volicer, School of Ageing Studies, University of South Florida, Tampa, USA

“You matter because you are you, and you matter to the end of your life, and we will help you not only to die peacefully but to live until you die.”

Dame Cicely Saunders
Namaste
“To Honor The
Spirit
Within”

Namaste Care – Key Elements

• “Honouring the spirit within”
• The presence of others
• Comfort and pain management
• Sensory stimulation: 5 senses
  ○ Sight, touch, taste, hearing, smell
• Meaningful activity
• Life history
• Care staff education
• Family meetings
• Care of the dying and after death care

Hand massage
Friends: dolls & life-like animals
Music
Hydration & food treats
Stimulation with appropriate DVDs
Nature & the senses
Textures
Namaste Care Programme

- Best practice dementia care
  - enriching quality of life for the individual
- Best practice end of life care
  - providing comfort, dignity and a good death
- Support for residents, family and friends and care staff
- Cost neutral –
  - no new staff/new space/expensive equipment
- 7 days a week / before and after lunch

An action research study

Aim
To implement the Namaste Care programme in six dementia care homes with nursing in the UK, and evaluate its effect on the quality of life of people with advanced dementia in care homes, and those who care for them, families and staff.

Design & methods

Prospective mixed methods action research study involving 6 nursing homes.

Care Homes divided into two tracks with three in each.

Data: Quantitative & qualitative data – before, during and after the study
- Residents, care home staff, families

Implementation of Namaste Care by Professor Simard

- Introductory workshop for all CH managers & key champions introducing Namaste Care
- Visited each CH twice
  - in-house education about Namaste Care (all staff)
  - in-house demonstration/role modelling with staff and residents
- Each CH received 2 copies of Namaste Care
Quantitative data

Residents
- Identified by nurse managers
- Recruited through the consultee process.

Inclusion criteria:
- A dementia diagnosis
- Bedford Alzheimer’s Nursing Severity Scale score of 17+

Primary research measures for residents were:
- Neuro-psychiatric Inventory - Nursing Home version (NPI-NH)
- Daloxplus-2 behavioural pain assessment scale.

Measures were recorded at baseline, and at 3 intervals of 1.2 months after the care programme started.

Qualitative data

Care staff - focus groups pre-implementation & post-evaluation period in each care home

Relatives - focus groups in each care home after evaluation period

Nurse managers – each interviewed after the evaluation period

Nurse researcher kept a reflective diary throughout the research study.

Namaste Project Care Homes

<table>
<thead>
<tr>
<th>CH</th>
<th>No. Beds</th>
<th>Management Structure</th>
<th>Manager</th>
<th>Namaste Care Programme</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Medium</td>
<td>Corporate</td>
<td>Manager and regional manager left</td>
<td>Disengaged, before starting</td>
</tr>
<tr>
<td>B</td>
<td>Large</td>
<td>Corporate - not for profit</td>
<td>Manager left, project staff</td>
<td>Still working to achieve Namaste (mornings)</td>
</tr>
<tr>
<td>C</td>
<td>Small</td>
<td>Family owned</td>
<td>Owner took over project</td>
<td>Nourishing Namaste</td>
</tr>
<tr>
<td>D</td>
<td>Medium</td>
<td>Corporate</td>
<td>Manager &amp; deputy left, replaced by new project</td>
<td>Nourishing Namaste</td>
</tr>
<tr>
<td>E</td>
<td>Small</td>
<td>NHS</td>
<td>Manager on development programme for 4 weeks</td>
<td>Nourishing Namaste</td>
</tr>
<tr>
<td>F</td>
<td>Small</td>
<td>NHS</td>
<td>Project stopped, project stopped</td>
<td>Nourishing Namaste</td>
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What we found in the care homes...

- ‘Chaos and confusion’
- ‘Rushing about’ - focus on priority needs
- Compassionate staff but burdened by care
- Lack of trust & poor communications
- Deaths often experienced as sudden and ‘unexpected deaths’.
Challenges and facilitators

- Needs strong committed leadership
  - Engagement of the wider team
  - Protecting the programme and the champions
- Good medical and nursing care must be in place
- Understaffing/shift patterns
- Routines and habits are hard to change
- ‘Seeing is believing’
- Reflection eg writing a mission statement

The effect of Namaste on NPI scores & severity of behavioural symptoms (aggression, agitation and behavioural problems)

Pain levels determined by the Doloplus-2 scale in five care homes

Severity of behavioural symptoms in subjects whose analgesic medications were increased or unchanged
Qualitative findings

Overarching & interconnected themes

Calmness: ‘Namaste is a feeling’

‘Seeing the person’

‘Reaching out to each other’

Well-being – residents, relatives & care staff

Taking off the gloves....

‘the power of touch’ & ‘seeing the person’

CA6 The very important things is that we are doing it without gloves, so they feel our body, our warm body. So the experience and feeling is totally different...

CA3 ...Intimate, intimate rather than with gloves, you know, because the gloves is between our skin and their skin. But now we touching them, body contact together, you know, they feel our warmness, we have to feel their own warmness...they will know someone is touching them.

[Care worker: Namaste Focus Group]

‘Reaching out to each other.....’

‘The biggest thing Namaste has given me is a different focus when visiting Mum. For many years now Mum hasn’t been able to communicate with us...at times she appeared to barely realise that I was there. I now know to do other things as well as talk to Mum, like show her old photos, brush her hair, feed her treats and moisturise her face and hands. This makes spending time with her easier and I feel I am making more of a connection with her and a difference in her life.’ (Relative CH D)

Namaste provides vision and structure

‘I think it has completely changed the way we approach care now. I think it has made my job easier because I had a vision of, you know, you have a vision of what you want in the home and what you want for your residents. Namaste has packaged that into a programme which has allowed me to get things across to the staff in a way they can understand’

[Manager’s interview CH C]
The Namaste Care programme and its potential for change

- Vision – focuses on values - 'honouring the spirit'
- Offers an alternative structure to care
- Offers guidance for 'being with'
- Gives permission for intuitive care
- Encourages new skills and creativity
- Fosters relationship centred care
- Opportunities for closer relationships between families
- Creates a positive framework for end of life care conversations and care

Conclusions

- The Namaste care programme can enhance quality of life for people with advanced dementia by decreasing behavioural symptoms

- Strong leadership and adequate staffing are necessary pre-requisites for introducing a care programme focusing on quality of life

- The Namaste Care programme provides a framework for developing a compassionate culture of care which does not require additional staff or expensive equipment

Toolkit

We are piloting a manual and running workshops to support care homes to implement Namaste.
Discussion Groups

1. New models for community palliative care

Group 1: New Models for Community Palliative Care (Kate Heaps)

1. Practicalities of the new service

- Single point of access via the coordination centre
- Eligibility for the service on paper is last year of life but in practice it is more flexible than that and includes any patient with a life limiting illness and not necessarily patients requiring specialist palliative care.
- All those patients currently receiving specialist palliative care will be recorded in the coordination centre. It is possible to dip in and out of the service but not to dip in and out of the coordination centre.
- The aim of the new service is to deliver personal care to patients not on specialist palliative care register. There are only small numbers in this patient group. Characteristics of this group: COPD, heart failure, non-malignant conditions with multiple comorbidities.
- Referrals:
  - Mainly from hospital but also from community nurses
  - Would like to have changed the referral route but this is difficult because the hospice sits across two boroughs (Greenwich and Bexley).
  - Referral points are not currently fully integrated.
- Good example: St Elizabeth’s Hospice in Ipswich changed whole care team (nurses and health care assistants) to improve integration. Unlike elsewhere they do not have separate teams for community nurses, night nurses, rapid response, specialist palliative care etc. At St Elizabeth’s they now have just two teams based on locality. Rotas are set up to cover different settings and patients are followed by the same practitioners. This was set up to improve integration and to enable people to remain in their home. It aims to be more responsive and patient focused.

1. Advance care planning with volunteers

- Initially a pilot project funded by comic relief. The beneficiaries would be the patients but also the volunteers. 80% of volunteers had to be older people.
- Volunteers were trained before they were interviewed which allowed for some self-selection and allowed for staff to get to know them first. Training is extensive (about 3-5 days)
- Volunteers receive a request for support from family member or health care professional.
- Volunteer visit patient up to 4 times (short-term intervention) to discuss end of life issues. Would allow time to talk over options, legal routes and also allow time in between visits for patients to discuss with their families.
- Outcome might be tangible in form of written document or might be simply the opportunity for difficult conversations with family members.
- GPs are informed when volunteer has been referred and then any pertinent or relevant outcomes or issues are communicated to GPs and recorded in medical notes.
- There is currently a problem with connection to Coordinate my care in Greenwich but once resolved will be included.
- There are plans to evaluate this on a larger scale (currently in discussion with CCG)
- Important data to collect for evaluation would be costs (for CCG), patient/carers views and professionals to determine what makes the difference.

Main points:
1) Importance of flexibility of the delivery of the service
2) Important group to focus on and widen access to is the generalist patients with no current contact with specialist palliative care but that may require assistance in the middle of the night.

2. Ensuring outcome measurements work in practice

Key messages:
- The aims of implementing outcome measures are to:
  — Improve clinical interaction;
  — Enable appropriate evaluation of services and;
  — Facilitate benchmarking and development of quality indicators
- We identified implementation science as a key to ensuring that outcome measurements work in practice. However, it is unclear what implementation is and in particular, what the ‘science’ in ‘implementation science’ is. A suggested definition is that implementation science is the study of the implementation of a programme or intervention, usually done while the implementation is on-going
- Barriers to outcome measurement in clinical practice and in research:
  - A lack of clinical buy-in was identified as a major challenge to the implementation of outcome measures
  - Suggestions to address challenges:
    - Highlighting the importance of outcome measurement to clinicians
    - Real time feedback of results and outputs to clinicians and patients, either face-to-face or via electronic media

3. Understanding families; the locus of decision making and the locus of care

1. Biggest challenges – clinical practice

- Despina’s research - we usually see families as responsible for everything, but they actually work as systems (distinct roles: decision makers, care delivery). Consistently followed over time unless there was an issue they needed to address. Different members – different problems.
- Often no consensus about what patient wants, what family wants.
- Lots of changing events – more about process, people think differently at different stages of illness trajectory.
- Intensive care – sudden events. They don’t know what to talk about. Health professionals need to create space to talk about these things. Patients and families don’t know where to start.
- Teaching in PC – the purpose of what we do is to create decision making. Dealing with symptoms to clear the ground to then deal with other issues. The creation of decision space is the job in hand. Empowering people to control aspects of dying.
- Who is the family? Who is important? Especially when patients can’t speak for themselves. Biological links sometimes override who is impt for pt.
- Despina’s research - What to look out for a) reassess all the time goals of pt and fam. These things change over time, if their priority has changed. B) Fighting for life/cure, change of focus on relations and what is impt in life/ they lose interest in treatment and care plans. Trigger for us to change gear. 3weeks-1week phase – symbolic interaction and start triggering dying (irrelevant to what we tell them – they can tell us what’s impt). Being sensitive to how people’s end of life priorities change.
- What’s really impt to people is what we should be dealing with. How do we empower staff to engage in this and find out what is really impt for pts/familes.
- Where would you like to die – pain management might not be as good at home as in hospital. Under what conditions do you want your life to end. Care provision at home not as good, do families and pt have time to talk together because they are providing all physical care. Rested enough to have emotional energy to sit and talk, what do they want.
- Lack of privacy. But this is an individualised thing. Permission to express yourself. People around also have to feel comfortable. You have freedom to make your mind up.
- Not whether conversations are had, but quality of them. Trying to get away from tick box culture and talk about the realities of what it will actually be like – practical/feasible?

2. Biggest challenges – research

- Where to do the interview – hospital environment vs. Home ‘where would you like to be interviewed?’ Dialysis patient – ‘I’ve already lost this time, interview me here’.
- Different environment, out of context, influence dynamics of interview
- How do you do research with more than one member?
- Sometimes easier for patient and carer to be interviewed together. More truth? Sometimes they challenge each other. You can get more out of the interaction between the two. Memory unreliable under emotional stress.
- More research on the floor of where the work is happening, conversations are happening, talking to family in waiting room. That’s where clinicians have to do their work.
- Exposure to clinical environment important for the quality of the interview.
- Emergency – timing of when to interview pts & carers. Intrusive vs getting meaningful data

4. Psychometric properties of an outcome measurement

What are the different aspects of psychometrics/psychometric properties?
Validity: Does the measure measure what it intends to measure?
1: Structural validity – factor analysis
- Requires high numbers (>100), ratio should be 10 participants per one item
- In palliative care, we therefore usually have to recruit from multiple sites
- Problem then are heterogeneous samples
2: Construct validity
- Hypothesis testing: Comparing to other measures /their subscales, convergent (scales that measure similar constructs to new measure should have high correlations) and divergent (scales that do not measure the same thing should have low/no correlation)
- Known-group comparisons: Contrasting subgroups in sample, i.e. those with high ECOG performance status versus those with low performance status
- What are the ‘standards’ when you test these aspects? Terwee et al: Certain number of hypotheses should be confirmed by the data
  - Need to think about criteria – i.e. when is something valid?
  - No clear criteria when a questionnaire is not valid!, bias seldom assessed in psychometric studies
3: Criterion validity: Rarely done as you need to have a gold standard measure which is widely accepted in the field, however, in palliative care we are interested in patient’s viewpoint and there is no gold standard for capturing patient experiences/family experiences
4: Cross-cultural validity
- Cross-cultural validity: Does it work/perform the same in different groups
- In palliative care: Does it work the same in different disease groups
Reliability
We’d expect outcome measures to work the way we want televisions to work – no matter who
switches it on, when it is switched on, how long it has been switched off for – it should switch on.
Different aspects to assess: Amount of error (SEM)
- Internal consistency (although strictly speaking not a form of reliability) is most often assessed
  using Cronbach’s alpha; “good” measure has $\alpha = \text{>85}$ - problematic because Cronbach’s alpha in a
  way assessed if all items measure the same thing – this, however, is less applicable in palliative
  care as the items are often intended to cover different domains, therefore alpha tends to be low in
  multi-dimensional scales
- Test-retest: if conditions don’t change, test result shouldn’t change. However, this is less useful
  in palliative care as conditions are always changing. Needs to have a small enough window in
  which condition doesn’t change
- Split-half: measures in palliative care too short
- Inter-rater reliability: Patient might give different answers
- Hypothetical scenarios
Clinically relevant: Being able to pick individual questions/subscales from instrument and
administer them without compromising validity
- clinical situation is often such that long questionnaires cannot be administered, clinicians want
to combine questions into their own surveys according to their needs
- Two approaches in psychometrics are classical test theory and item response theory
- Old approach: Classical test theory – validated whole measures and cannot say whether the
  individual question is valid
- Item response theory approach: New approach, can validate single items
In palliative care/quality of life measures you see two approaches to address this problem:
1) Modular measures
   - Modular: core + disease specific add-ons; usually short core measure which can be extended
2) Item banks
   - validated individual questions and description in which setting/population they can be used
   - EORTC group and PROMIS system are moving into this direction
   - Do not need always big numbers to do this work, although it helps
   - Can be extended into computer adaptive testing: computer presents respondent with next
     logical question given the answers to a few screening questions, computer chooses from a pool of
     items

5. Interventions for people with dementia in care homes

- Continuing changes in management, ownership & staffing in the care homes.
- Dealing with someone different each time you visit- bringing different priorities & ways of
  working
- Cared at home by private agencies who have no contact or input from other agencies
- No availability of core standards, poor level of training for staff in care home, not even
  knowledgeable about basic care needs
- Families do not always understand disease progression & what to expect
- For POS Dem study some care homes very keen others just overwhelmed
- Training does not work if management not on board with culture changes & are not
  supportive to this change
- Needs clear lead at CQC level, they need to be clear, but no evidence available at present
- Psychiatry very involved in care of people with dementia but not linked into palliative care
  locally to bring these skills & resources together
• Palliative care does not recognise how many now & in the future many more people with die with dementia or some degree of impaired cognition. ?60% of future population
• Every area of palliative care there should have a dementia champion?
• The Prime Minister Dementia Care Challenge-
• No always in health care professional’s interest to provide a clear diagnosis, more work-advanced care planning, not sufficient resources. Most people living in residential home never receive a formal diagnosis
• Book called “Who Cares” very old- need new one to be written with info that is up to date about dementia. Alzheimer’s society very good resource but all on line.
• Dementia awareness & training for all healthcare workers as part of updating
• Lack of resources & co ordination
• Importance of developing outcome measures so we can start to measure any improvement we try to make.
Presentation Feedback Summary

1. Delivering integrated care in the Community (Kate Heaps, Greenwich & Bexley Community Hospice)

2. Implementing Outcomes in Practice (Susanne de Wolf and Dr Simon Etkind, CSI)
3. PhD Thesis: The last months of living: an ethnographic study of the trajectories of illness and care of patients with advanced cancer in Greece (Dr Despina Anagnostou, CSI)

4. Development and validation of a myeloma-specific quality of life questionnaire - the MyPOS (Christina Ramsenthaler, CSI)
5. Namaste in Care Homes (Min Stacpoole, St Christopher’s Hospice)

![Bar chart showing feedback on session clarity and usefulness.]

**Workshops Feedback Summary**

1. **New models for community palliative care**

![Bar chart showing feedback on session clarity and usefulness.]
2. Ensuring outcome measurements work in practice

![Bar chart showing session clarity and usefulness](chart1)

3. Understanding families; the locus of decision making and the locus of care

![Bar chart showing session clarity and usefulness](chart2)
4. Psychometric properties of an outcome measurement

![Bar chart showing responses to clarity and usefulness of session]

5. Interventions for people with dementia in care homes

![Bar chart showing responses to clarity and usefulness of session]