Home from Home: a vision for the future in care homes
“Celebrating Quality Care”
28th September, 2018

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Primary Palliative Care Research Group
University of Edinburgh
Overview of my lecture:

- Comparing palliative care and geriatrics
- Very brief results from my PhD looking at palliative care and care homes
- How this informed taking part in GSFCH project
- Results from five years working with GSFCH programme
“Both make the whole person and his or her family the focus of care, while seeking to enhance quality of life and maintain the dignity and autonomy of the individual. Judicious use of investigations is advocated and both eschew unwarranted treatment while providing symptom control and relief of suffering. Both are necessarily multi-disciplinary and both are areas which prompt phobic reactions from society at large. Finally both Geriatrics and Palliative Care are new medical technologies which challenge the restorative, often aggressive and increasingly technological practices in technological areas of medicine.”  Mount, 2000
Cancer Trajectory

The Frailty Dementia Trajectory
Staff & residents in an older people's care home in London.
Photograph: Frank Baron
http://www.guardian.co.uk/society/2009/jul/08/residential-homes-older-people-care
Developing high quality end of life care in care homes: an action research study (Hockley 2006; 2012)

What problems do staff experience in caring for dying residents? What interventions do staff want to implement?

Action Research study to develop quality end of life care. An initial ethnographic phase found ‘dying to be peripheral to the relatively weak care home culture’. Two actions, inductively derived, were interpreted using Habermas’s theory of SYSTEM & LIFEWORLD:

- Experiential learning through reflective de-briefing sessions following a death supported and valued the LIFEWORLD of staff
- An integrated care pathway (ICP) for the last days of life as a SYSTEM to embed change

Simultaneous contribution to social science and social change

RdBSs ...

valued the ‘LIFEWORLD’ of staff and at the same time helped them learn about death & dying by reflecting on practice.

ICP ...

an important SYSTEM to anticipate the complexities of care in the last days of life within the world of NHs

A DEVELOPMENT MODEL

Re-coupling of the ‘lifeworld’ and ‘system’ (Habermas 1987) to optimise high quality care at the end of life in NHs
Changing cultures in care homes  (Kitson et al 1998; Hockley et al 2010; Kinley et al 2014)

- Kitson et al argue the important relationship between:
  - CONTEXT – ‘low’ ‘high’
  - EVIDENCE – ‘low’ ‘high’
  - FACILITATION – ‘low’ ‘high’

- That there has to be two ‘highs’ to counteract ‘low’

- Care Homes
  - CONTEXT – ‘low’
  - EVIDENCE & FACILITATION – ‘high’
Care Home Project & Research Team

- In 2008 St Christopher’s Care Home project team became a regional centre for the Gold Standards Framework for Care Homes
- Team commenced 2008
  - 5.5 FTEs covering 5 clinical commissioning groups
  - 1.4 million population
  - 71 nursing homes + 75 residential care homes for older people
- Development of end of life care through implementation of GSF (system) for greater PC approach + support of staff (lifeworld)
Process of GSFCH Implementation: Preparation – Training – Consolidation – Accreditation

<table>
<thead>
<tr>
<th>Stage I Preparation</th>
<th>Stage II Training</th>
<th>Stage III Consolidation + Sustainability</th>
</tr>
</thead>
<tbody>
<tr>
<td>3-6 months</td>
<td>workshops in 9 months</td>
<td>9 – 12 months</td>
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</tbody>
</table>

- **Stage I Preparation**
  - Enrolment of Care Homes
  - Awareness Raising Meeting
  - ADA Before
  - Local Coordinators Meetings

- **Stage II Training**
  - Workshop 1
  - Workshop 2
  - Workshop 3
  - Workshop 4

- **Stage III Consolidation + Sustainability**
  - ADA After
  - Ongoing ADA
  - Final Appraisal
  - GSFCH Accreditation
Comparison of data on DNaCPR; ACP & ICP – 2009 to 2012
Care Home Project Team, St Christopher’s, London

<table>
<thead>
<tr>
<th></th>
<th>PCT 1</th>
<th>PCT 2 &amp; 3</th>
<th>PCT 4</th>
<th>PCT 5</th>
<th>Total</th>
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<tbody>
<tr>
<td><strong>DNaCPR:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2009/10</td>
<td>43% (n=155)</td>
<td>41% (n=265)</td>
<td>68% (n= 384)</td>
<td>54% (n=271)</td>
<td>52%</td>
</tr>
<tr>
<td>2010/11</td>
<td>45% (n=218)</td>
<td>74% (n=329)</td>
<td>75% (n= 435)</td>
<td>71% (n=397)</td>
<td>66%</td>
</tr>
<tr>
<td>2011/12</td>
<td>75% (n=214)</td>
<td>84% (n=284)</td>
<td>86% (n= 492)</td>
<td>76% (n=361)</td>
<td><strong>80%</strong></td>
</tr>
<tr>
<td><strong>ACP:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2009/10</td>
<td>48% (n=155)</td>
<td>44% (n=265)</td>
<td>60% (n= 384)</td>
<td>51% (n=271)</td>
<td>51%</td>
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<tr>
<td>2010/11</td>
<td>62% (n=218)</td>
<td>61% (n=329)</td>
<td>74% (n= 435)</td>
<td>63% (n=397)</td>
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<td>83% (n=492)</td>
<td>79% (n=361)</td>
<td><strong>75%</strong></td>
</tr>
<tr>
<td><strong>ICP for last days:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2009/10</td>
<td>33% (n=155)</td>
<td>5.5% (n=265)</td>
<td>44% (n=384)</td>
<td>17% (n=271)</td>
<td>25%</td>
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<tr>
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<td>51% (n=284)</td>
<td>72% (n= 492)</td>
<td>59% (n=361)</td>
<td><strong>63%</strong></td>
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Comparison of place of death across nursing care homes

<table>
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<tr>
<th>Year Range</th>
<th>Percentage</th>
<th>[n] Deaths</th>
<th>NHs</th>
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<tbody>
<tr>
<td>2007 / 2008</td>
<td>57%</td>
<td>324</td>
<td>19</td>
</tr>
<tr>
<td>2008 / 2009</td>
<td>67%</td>
<td>989</td>
<td>52</td>
</tr>
<tr>
<td>2009 / 2010</td>
<td>72%</td>
<td>1071</td>
<td>53</td>
</tr>
<tr>
<td>2010 / 2011</td>
<td>76%</td>
<td>1375</td>
<td>71</td>
</tr>
<tr>
<td>2011 / 2012</td>
<td>78%</td>
<td>1351</td>
<td>71</td>
</tr>
<tr>
<td>2012 / 2013</td>
<td>77%</td>
<td>1375</td>
<td>72</td>
</tr>
<tr>
<td>2013 / 2014</td>
<td>76%</td>
<td>1232</td>
<td>72</td>
</tr>
<tr>
<td>2014 / 2015</td>
<td>79%</td>
<td>1474</td>
<td>76</td>
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</table>
## Type of death

[n=2369 – Kinley et al, 2013]

<table>
<thead>
<tr>
<th>Type of Death</th>
<th>Definition</th>
<th>Diagnosis/Conditions</th>
<th>Percent</th>
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</thead>
<tbody>
<tr>
<td>Sudden</td>
<td>When a resident collapsed &amp; died or found to have died totally unexpectedly</td>
<td>Diagnosis of cancer, Parkinson’s disease, motor neurone disease or admitted specifically for terminal care</td>
<td>4.3%</td>
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<tr>
<td>Acute</td>
<td>When deterioration occurred over a few days i.e. Following fractured femur or extension of stroke</td>
<td></td>
<td>19.2%</td>
</tr>
<tr>
<td>Terminal</td>
<td>Diagnosis of cancer, Parkinson’s disease, motor neurone disease or admitted specifically for terminal care</td>
<td></td>
<td>26.2%</td>
</tr>
<tr>
<td>Dwindling</td>
<td>Slow deterioration over a matter of weeks/months</td>
<td></td>
<td>50.3%</td>
</tr>
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</table>
Lessons we have learnt when developing end of life care in care homes

- Important to empower Care Home staff – not take over
- Any development has to be collaborative with a ‘top down’ + ‘bottom up’ strategy
- Importance of developing practice through various interventions but sustainability is not without cost
- End of life care for frail older people in care homes is different from SPC
- Involvement of the whole m/disciplinary team:
  - GPs; CPNs; psycho-geriatricians; SPC; district nurses (RHs)
Impact of population ageing

- The disabled older population will increase by over 80% and those with dementia by 50% by 2030 (Jagger et al 2009)

- By 2040, it is predicted that 40% UK population will die in care homes (Bone et al, 2017)

Sustainability is not without cost!
(Hockley & Kinley, IJPN 2016)

However, sustainability can be cost effective!!
To bring a sea-change to the perception of care homes both public + professional just as hospices brought a change in the perception of end-of-life care for people with cancer.
Thank you!
Any questions?

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References:
Hockley J (2014) Learning, support and communication for staff in care homes: benefits of reflective debriefing groups in two care homes to enhance end-of-life care. Journal of Older People Nursing.