What school communities want from their local hospice: the findings of an action research study between a hospice and primary schools

Dr Sally Paul
School of Social and Political Science
University of Strathclyde
sally.paul@strath.ac.uk

Aims

- Discuss the background to PhD research (my PCSW journey)
- Outline PhD research process, resulting practice developments and research findings
- Provide some (more) motivation towards developing community work as part of the palliative care social worker role
Background: the start of my PCSW journey

The PhD research

**Aims:**
1. To understand the extent to which a social taboo exists around talking to children on death, dying and bereavement in the school setting.
2. To explore and develop practice between the hospice and schools that facilitates conversation and education with children on death, dying and bereavement.
Community engagement and palliative care: policy and literature developments

Numerous terms and meanings

- Community engagement, development, participation, involvement
- (New) Public health approaches
- Health promoting palliative care
- Compassionate communities
**Do palliative care services value social approaches to end of life care?**

- Scoping survey completed to capture the range of practice currently being undertaken between palliative care services and their community
- 66% services responded (146 out of 220 services)
- 60% said social approaches were a **priority** for their service

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**Range of projects undertaken**

- Working with schools about loss, death, dying and/or hospice care: 107
- Engaging with local media on issues related to loss, death, dying and/or hospice care: 101
- Providing public education and awareness events: 89
- Attending community events as a hospice, such as markets or festivals: 87
- Supporting community dialogue about end of life care issues: 68
- Working with faith groups around loss, death, dying and/or hospice care: 65
- Engaging with local businesses on issues related to loss, death, dying and/or hospice care: 47
- Other: 16

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Paul and Sallnow (2013) Public health approaches to end-of-life care in the UK: an online survey of palliative care services, BMJ S&PC
Which projects were successful and why?

<table>
<thead>
<tr>
<th>Projects</th>
<th>Description</th>
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| Engaging with community groups and organisations | ■ Providing education and information  
■ Sharing expertise  
■ Raising the service profile  
■ Fundraising  
Examples of groups included: businesses, faith groups, nursing homes, professionals, and other charities. |
| Work with schools | ■ Providing bereavement support with individuals and staff.  
■ Engaging pupils in conversations on palliative care, death, dying and bereavement. |
| Awareness Raising | Projects to raise awareness of:  
■ The hospice  
■ Health issues, such as cancer  
■ End of life care issues |

General comments

**Pivotal**

“Hospices have a pivotal role in enabling communities to cope with end of life care issues”

■ Could have influence inequitable care  
■ Widening access  
■ Strong existing links with local communities  
■ Resource of expertise in end of life care  
■ A responsibility of hospices

**Utopian**

“like reaching for a rainbow”

■ Lack of:  
  ❑ Resources  
  ❑ skills  
  ❑ funding  
■ Must be balanced with service provision
Spectrum of engagement in end-of-life care: developing community capacity

Inhibiting factors:
- Low level of power sharing by service
- Work initiated by organisation
- In response to top-down requirements
- Organisation leads on work
- Public as a series of individuals
- Opportunistic work
- Low level of community capacity

Supporting factors:
- High level of power sharing by service
- Work initiated by community
- In response to community-identified need
- Communities lead on work
- Public as whole communities
- Proactive work
- High level of community capacity

Inform, Consult, Co-production, Collaborate, Empower

Increasing community capacity and quality of care in EoLC


The research process: an action research approach

Key features of action research:

- Focuses on participation and change
- Three phases:
  - Exploring/planning
  - Action
  - Evaluation
- A research journey: walking and learning together
The research setting and participants

- Two primary schools
  (1x catholic and 1x non-denominational)

- Time frame: over one school year

- Participants: children (9 – 12 years), parents, teachers and hospice staff

Phase 1: exploring/planning

What school staff said …..

“old Ostrich syndrome”
What children said …..

“What happens to the corpse?”

“How do you deal with death and dying?”

What parents said …..

LET US KNOW!
What Hospice staff said …..

Phase 1 (planning): practice developments

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<td>(1) Integrate health and death education throughout the curriculum.</td>
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<td>(4) Carry out activities about the Hospice during the Hospice ‘Schoolfriends’ fundraising event.</td>
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## Phase 2: action

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Findings: the role of hospices working with primary schools

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<th>Goal</th>
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<td>Awareness Raising</td>
<td>- Dispel myths associated with hospice care, end-of-life care and bereavement.</td>
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<tr>
<td>Education and training</td>
<td>- Increase awareness of childhood bereavement.</td>
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<tr>
<td></td>
<td>- Develop capacity of school staff and/or parents/carers to manage childhood bereavement within school and at home.</td>
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<tr>
<td>Leadership in death education and bereavement</td>
<td>- Influence policy makers and/or management teams to establish death, dying and bereavement affirming activities, policies and procedures.</td>
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Some thoughts …

- The action research process was important: engagement -> participation -> ownership -> autonomy
- Hospices have existing positive relationship with the community that can be optimised
- The developed practice requires:
  - A reorientation of service delivery (proactive AND reactive)
  - Transferring knowledge, expertise and control
We can’t do it alone