The Pressure and Privilege of Providing Palliative Care Professionally to friends, colleagues and family

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Introduction

- Population ~85,000

- Regularly care for friends, family, former colleagues

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Background

- Burnout no higher in Palliative Care than other specialities[1]

- Death of people with whom professionals have grown close[2]
  - Emotionally distressing; work-related stress
  - Job satisfaction

- Distress & psychiatric morbidity high in informal carers of Palliative Care patients[3]

[1] Pereira et al., 2011; [2] Martens, 2009; [3] Rumpold et al., 2015

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Aims

- To what extent is there a relationship between caring for friends/colleagues/family and burnout?

- What are the challenges and opportunities of providing palliative care to loved ones?

- How do professionals cope with this?

Methods

Phase 1: questionnaire to IoM & East Cheshire Hospice

- Estimate number of patients in the past year who have been friends/family/colleagues

- Maslach Burnout Inventory[4]

- Multiple-choice questions:
    1. Rank top 3 sources of burnout
    2. Rank top 3 protective factors against burnout

[4] Maslach et al., 1996

Phase 2: focus groups

- Two focus groups:


    – Challenges
    – Opportunities
   – Emotional, spiritual, psychological & professional coping strategies

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Results

	Hospice Isle of Man	Control Hospice
No. of Staff responses	36 (48%)	23 (52%)
Sex	35 F, 1M	23 F
Experience in Palliative care work	More	Less

Chart to show age distribution of participants

■ Control Hospice ■ Hospice IOM

under 30: 8% / 11%
31-40: 21% / 11%
41-50: 33% / 22%
51-60: 33% / 49%
>60: 4% / 8%

Age in years

Professional Groups

Registered Nurses: 38
HCAs: 12
Doctors: 3
Clinical Managers: 2
PAMs: 4
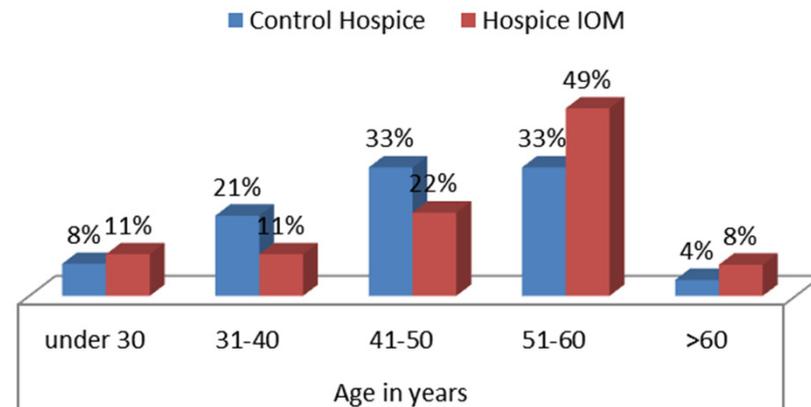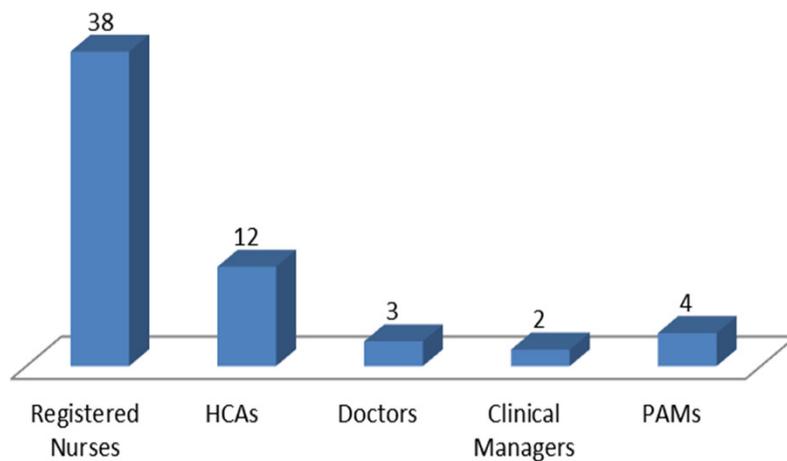
Chart to show distribution of years of Palliative Care Experience

■ Control Hospice ■ Hospice IOM

less than 1: 13% / 11%
1year to 3 years: 33% / 8%
4 years-10 years: 25% / 38%
11 years to 20 years: 25% / 35%
over twenty years: 4% / 8%

Years of palliative care experience
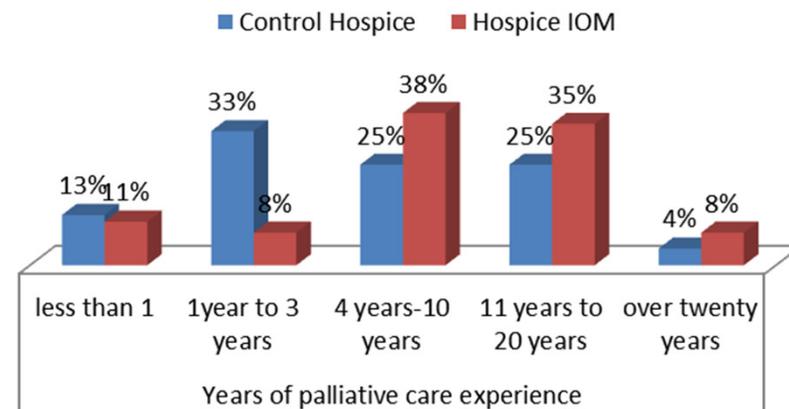
Results

- Burnout scores were <u>low</u> across all areas

Proportion of participants reporting low, medium and high levels of burnout

■ Low burnout ■ Medium burnout ■ High burnout

- Emotional exhaustion: 95%, 5%, 0%
- Depersonalisation: 78%, 17%, 5%
- Achievement: 73%, 12%, 15%
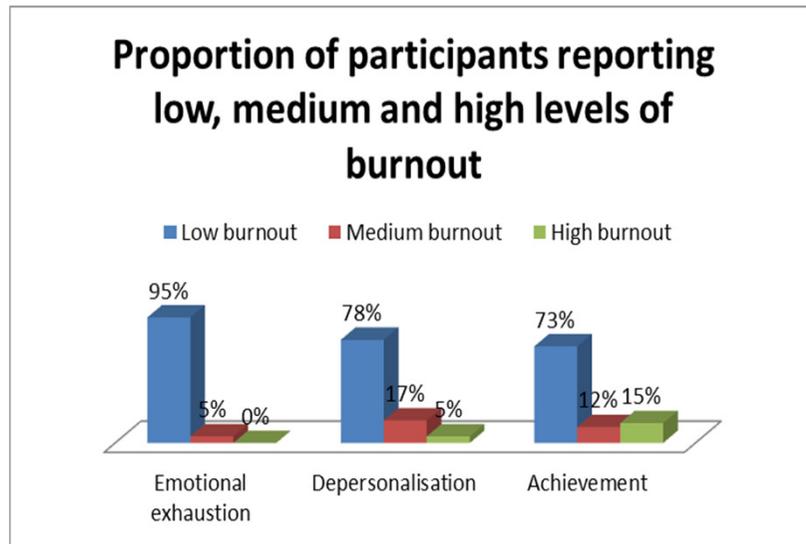
- Statistical analysis showed <u>no relationship</u> between caring for family/friends/colleagues and any aspect of burnout

- <u>No evidence of difference between the two hospices</u> in number of loved ones cared for

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Causing Burnout

**Chart to show factors felt to be important in increasing the risk
of burnout in palliative care professionals**

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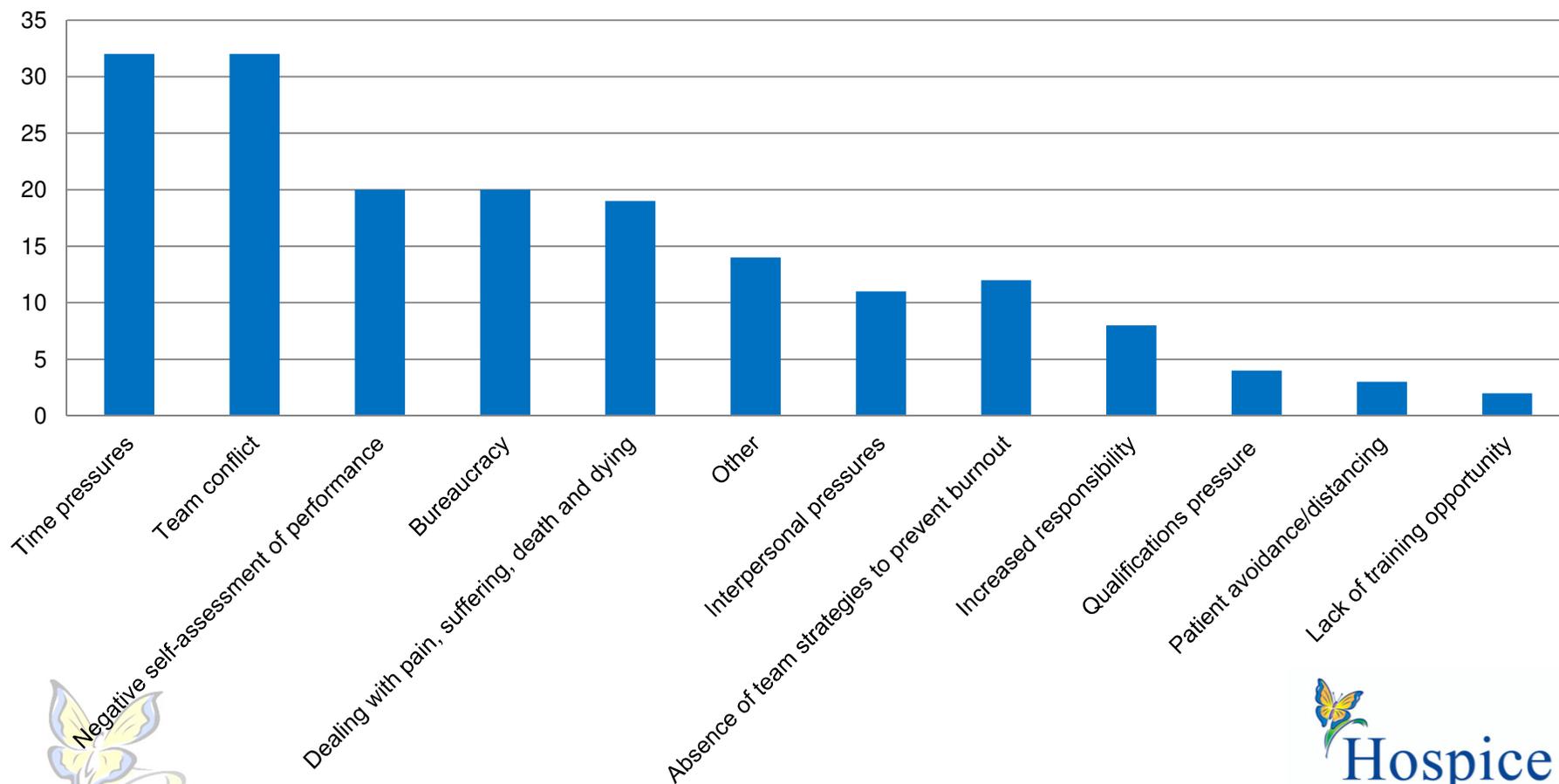
Reducing Burnout

Chart to show factors felt to be important in reducing the risk of burnout in palliative care professionals
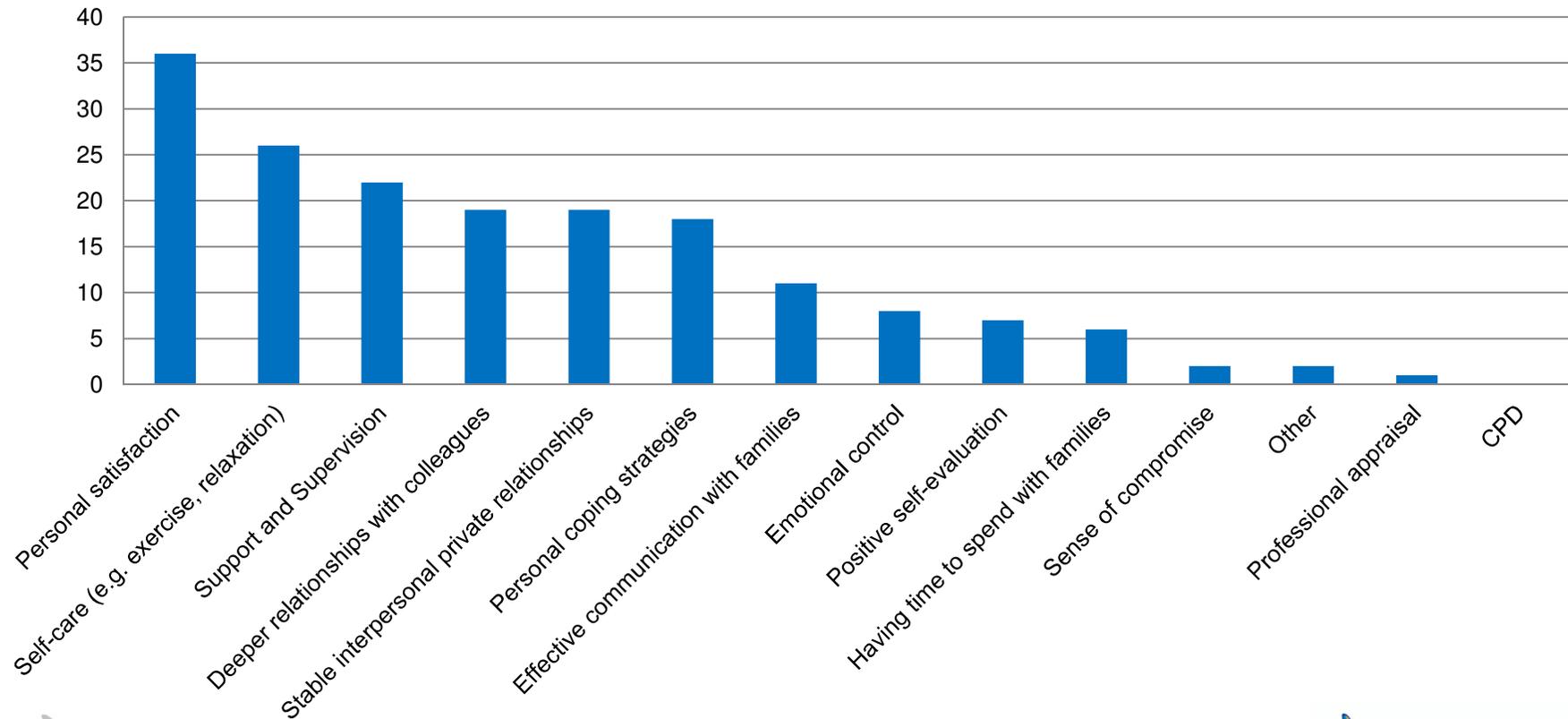
Focus Groups

8 participants

4 main themes emerged

- The pressure of high standards
- Ethical dilemmas about provision of care
- The privilege and cost of providing care – for the patient, family, and professional
- Drawing on a range of coping strategies

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Theme 2: Ethical dilemmas about provision of care

"I think it's wrong to nurse someone you know in an acute setting but I suppose it's up to individual staff to decide, depending on how close you are to the patient"

"I would ask if they were happy about me providing care for them"

"it's very difficult in acute settings especially for personal care, privacy and so on, a lot of people are not comfortable with this"

"is that a logical decision or is that just because you have been put under huge pressure?"

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Theme 3: The privilege and cost

"I don't think you can ever get over your first experience of death of someone that you know"

"I have seen the son since then and he has blanked me, clock you in [a shop] and turn away…you bring it all back for them"

"Sometimes you've already got the emotional connection and you know how to approach that person"

"although the ante is up, I have always felt that the people I have known have always been pleased that I could do that something for them….it's still a special thing that you can be there at that time and support them"

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Theme 4: Drawing on a range of coping strategies

"well somebody or one of your peers who understands how you're feeling, and maybe it's just that one person that you talk to"

"I think we're all quite self-aware practitioners"

"it's about being professional enough to recognise that these are not friends in that situation and it's sensible to have a more professionally detached role"

"it's something those of us who have been there are aware of and are very good to look out for other members of the team and always protect them if we see they are getting a bit too involved"

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Limitations
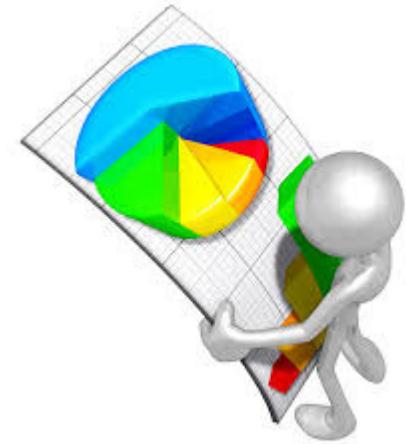
- Small sample size

- Floor effects

  – More sensitive measure to pick up more subtle effects of distress?

- Response bias

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Implications for Practice

- May be common to care for family / friends / colleagues in other locations

- Awareness of potential high pressure and high standards → implications for teams / colleagues

- Reflective practice & self-awareness

- Boundaries and asking permission

- Formal and informal support systems essential

- Managers: team conflict, time pressures, bureaucracy, & negative self-Ax are rated as top stressors

- Personal enrichment

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Thank you

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