

All Ireland International Conference

PUSHING BOUNDARIES IN PALLIATIVE AND END OF LIFE CARE

6 & 7 October 2009

Beyond Palliative Care – Supportive Care for People with Dementia

Dr Julian C. Hughes

Consultant in old age psychiatry and honorary professor of
philosophy of ageing

Northumbria Healthcare NHS Foundation Trust and
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Plan

- I. Characterizing care: the move to supportive care
- II. Ingredients and issues in supportive care
- III. Policies and practice of supportive care

Advertisement: main reference for rest of talk!

Supportive care for the person with dementia

Julian Hughes,
Mari Lloyd-Williams, and
Greg Sachs (eds)
Oxford University Press (2010)
(But due out in November 2009)

1. Characterizing care

A conceptual problem

- How do we characterize the care, owed to people with dementia, in such a way as to capture all its possible, desirable and necessary aspects?

Possible models

- Biomedical
- Person-centred
- Palliative
- Supportive

Is palliative care necessary? (1)

- McCarthy et al (1997)
 - ❑ 40% of people die in the community
 - ❑ <2% of people in hospices have dementia
 - ❑ Suboptimal treatment of symptoms
 - ❑ Carers need considerable support pre-bereavement
 - ❑ a host of common symptoms and signs experienced by people with dementia in the last year of life: confusion, urinary incontinence, pain, low mood, constipation and loss of appetite.

Is it necessary (in the USA)? (2)

- Mitchell et al (2004)
 - Greater use of non-palliative interventions
 - Inadequate treatment of some symptoms
 - Lack of advance care planning

Is it necessary (in the UK)? (3)

- Retrospective case-note studies demonstrate inadequate palliative care in both psychiatric and acute hospital wards
 - (Lloyd-Williams, 1996; Sampson *et al*, 2006)

Dementia in the acute hospital (Sampson et al, 2009)

- Six-month longitudinal cohort study: 617 people over 70 years
- 75 people died in index admission
- Over 3x as many people with dementia (18%) and 5x as many people with MMSE scores of 0-15 (24%) died; association strong after controlling for age and severity of acute illness [No dementia, deaths = 7.9%]
- The prevalence of dementia (91.9%) and cognitive impairment (80%) was very high in participants admitted from nursing homes

Seemingly yes!

- *“Every person with a progressive illness has a right to palliative care”* (WHO, 2004)
- *“Lack of palliative care for non-cancer sufferers ... greatest inequity of all in palliative services”*
(Health Committee of House of Commons, UK, 2004)

What might palliative care in dementia look like? (1)

- Palliative care approach
- Palliative interventions
- Specialist palliative care
- Dementia care
- ?
- Terminal care

What might it look like? (2)

- Palliative care approach
- Palliative interventions
- Specialist palliative care
- Dementia care
- Behavioural and psychological signs of dementia
- Terminal care

Questions for palliative care:

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Questions for palliative care:

- Is not the palliative care approach in connection with dementia no more than good quality (old fashioned) person-centred dementia care?
- What is it that is distinctive about palliative care over the whole course of a chronic disorder?
- Once it moves away from its roots in caring for the dying, 'palliative care' can start to seem like (albeit laudable) flag-waving. (Should it wither away?)

Some answers

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 - Non-curative?

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- Need for expertise in dealing with the end of life
- There is something that does define palliative care across the course of a chronic illness
 - Non-aggressive (is it?)
 - Being with (but we do to)
 - Non-curative?
 - End-of-life (effect on patients?)
 - Spiritual?

A suggested solution: supportive care

- ‘... it has been argued that palliative care, as a component of comprehensive supportive care, can play a part at all stages of disease. In many cases, there is an overlap of curative and life-prolonging therapy and then a further overlap as life-maintaining priorities take over....’

Continued...

- ‘...At all stages there is a place for supportive care, ... If we use this approach, seeing palliative care as having a contribution – within a supportive care framework – even when curative or life-prolonging therapy is the first priority of clinicians, then the contribution of palliative care to dementia care becomes more relevant throughout the illness.’

Small, N., Downs, M. and Froggatt, K. (2006). Improving end-of-life care for people with dementia – the benefits of combining UK approaches to palliative care and dementia care. In: Bère M. L. Miesen and Gemma M. M. Jones (eds), *Care-Giving in Dementia – Research and Applications, Volume 4*, Routledge, London and New York; pp. 365-392.

Supportive care

Supportive care

- Multidisciplinary

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- Multidisciplinary
- Interdisciplinary

Supportive care

- Multidisciplinary
- Interdisciplinary
- Possibly virtual

Supportive care

- Multidisciplinary
- Interdisciplinary
- Possibly virtual
- No dichotomies:
 - cure/care
 - high tech/low tech
 - biological/social
 - patient-centred/carer-centred
 - 'being with'/'doing to'
- Continuity of care

2. Ingredients and issues

Biological issues

- Understanding underlying biology
- Genetic influences
- Other biological risk factors
- Early diagnosis and importance of diagnostic competence
- Treatment appropriate to condition, symptoms, and time
- Recognition of brain frailty and consequent susceptibility to confusion
- Vulnerability to adverse effects of drugs
- Management of specific symptoms (e.g. pain, dysphagia, constipation, and contractures)
- Nutritional issues
- Mobility issues
- Maintaining function

Psychological issues

- Genetic counselling
- Sympathetic, emotional support to person with dementia and carers
- Support of cognitive skills
- Encouraging enjoyment
- Understanding carer burden and need for carer support
- Therapeutic relationships
- Comfort
- Maintenance of well-being
- Strategies for everyday living

Social issues

- Environmental risk factors
- Impact on family and family dynamics
- Meaningful activities (e.g. music, dance, and art)
- Community support (e.g. home care, day care, and respite care)
- Stigma and need for education
- Financial issues
- Legal issues, including wills
- Accommodation issues
- Importance of communication
- Safety
- Individual care packages
- Encouraging healthy lifestyles

Ethical and spiritual issues

- Acknowledging and supporting spirituality
- Regard to overall quality of life;
- Promoting dignity
- Personhood and person-centred care
- Moral support
- Advance care planning
- Maintaining autonomy
- Specific issues: withholding and withdrawing, use of antibiotics, ANH, resuscitation

Advance care planning

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- Lower incidence of advance care directives in dementia compared with cancer (Mitchell et al 2004)

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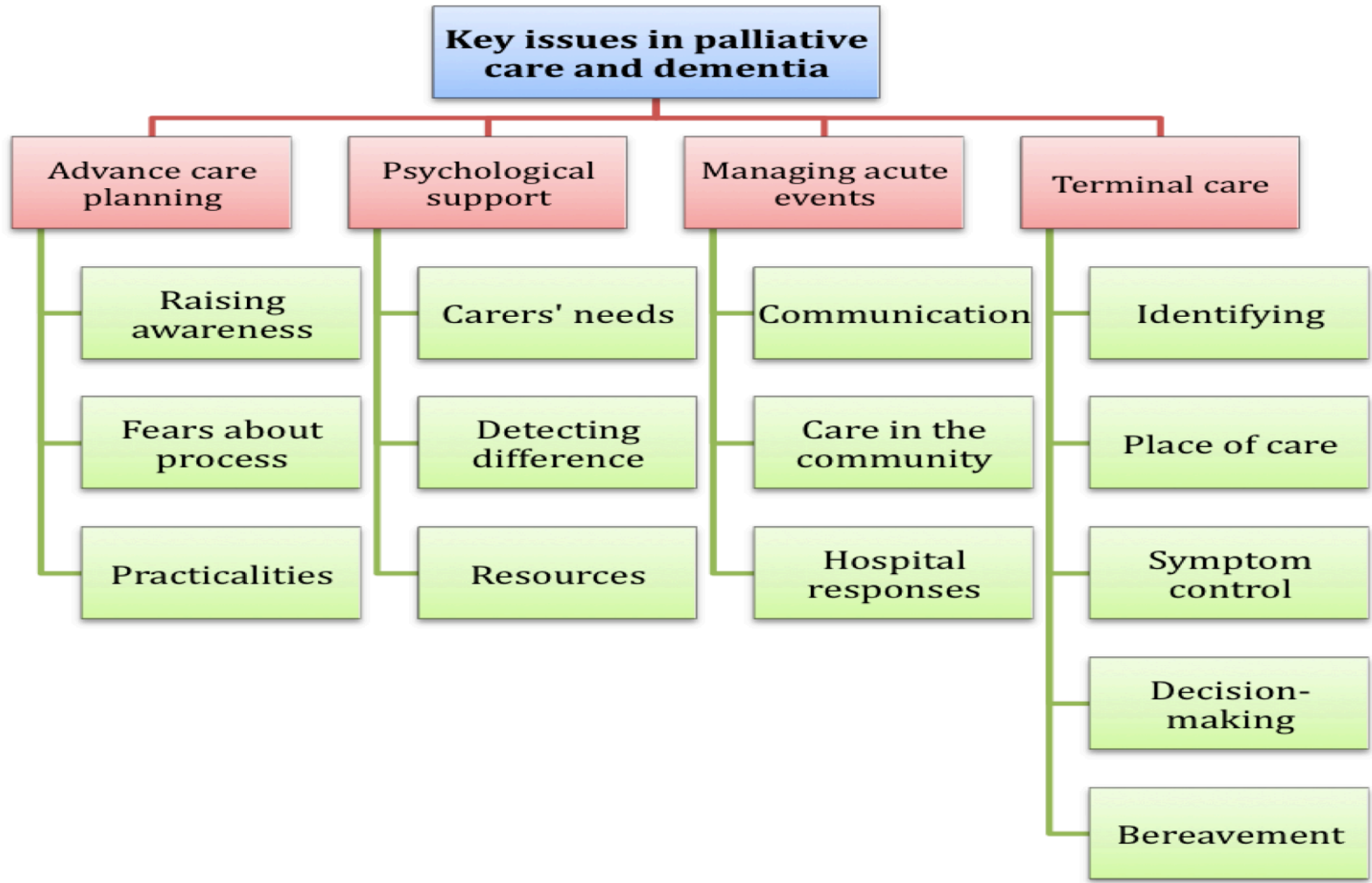
Advance care planning

- Lower incidence of advance care directives in dementia compared with cancer (Mitchell et al 2004)
- Reduced hospital admissions (25%) in advanced dementia (Caplan et al 2006)
- Older people, with or without dementia, are capable of making decisions about advance care planning (Karel et al 2007; Fazel et al 1999)

Ingredients of supportive care in dementia

- Coordination and integration
- Continuity of care
- Interdisciplinary care
- Flexible support
- Comprehensive care
- Palliative care
- Proper training and support
- Practical, emotional, moral, and spiritual support
- Changing support
- Community support
- Liaison services to hospital and other institutional settings
- Research and audit/quality improvement

Themes from North Tyneside consultation



3. Policies and practice of supportive care in dementia

Curative intent

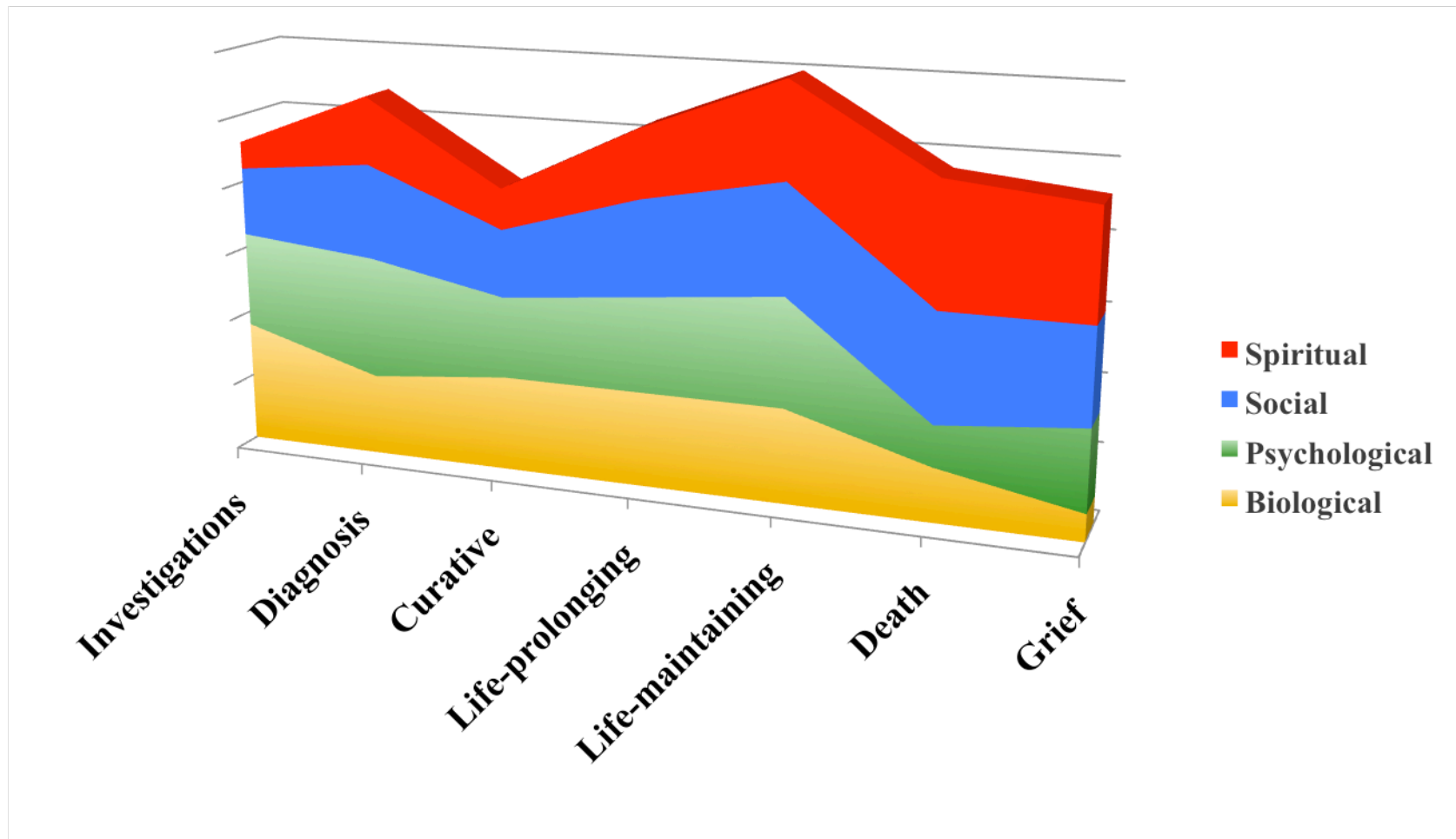
- Curing dementia
- Treating other geriatric syndromes: falls, delirium, depression
- Preventing illness and disease
- Shifting goals of care: palliative cures (e.g. antibiotics)

Layers of care

- Reflecting breadth of personhood: situated embodied agent view of the person
 - Biological
 - Psychological
 - Social
 - Spiritual
 - Cultural
 - Historical
 - Moral
 - And so forth ...

Supportive care

(Figure 32.1 in *Supportive Care for the Person with Dementia* (eds. Hughes JC, Lloyd-Williams M, Sachs GA.) OUP, Oxford)



Logistical steps

- Key worker, care co-ordinator, dementia care adviser
- The role of GP (Gillie E. Evans and Louise Robinson)
- Croydon model (Victor Pace)
- Admiral nurses
- PEACE programme (Shega and Sachs)

Final Conclusions (1)

- The palliative approach, coupled with person-centred care, under the umbrella of supportive care, provides a framework for how end-of-life care should be provided for people with dementia
- "But we need to consider: what do models do?"
 - Guide thought and action
 - Make a political statement

Final Conclusions (2)

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- What does palliative care offer that is really useful to dementia specialists?
 - Advance care planning
 - Management of acute events
 - Care of the dying
 - Spirituality
 - Bereavement

Thank You