Dying, Dignity and Dementia

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It wasn't until she went into the final care home in June 2010 that I could relax about her care, because, as I said, they had the best provision for it, and I felt she was treated as an individual. (daughter)

It's left us burdened with the care system like this… I'd have turned our dining room into a bedsit for her regardless of what the doctors said. God yes, my husband cries about it. He gets so distressed. For months since she died I find it very hard to sleep. I feel I let her down (daughter)

Dementia and end of life

- 850,000 people in the UK (1.3% of total population; 1 million by 2025; 2 million by 2051) (Prince et al 2014)
- Total UK costs: £26.3b (higher than cancer, heart disease or stroke) (Prince et al 2014)
- 670,000 family carers = £11b in care (Alzheimer's Society, 2014)
- 30% of people over the age of 65 die with a diagnosis of dementia (Brayne et al, 2006)
- 53% die in a care home and 40% in hospital (Sleeman et al, 2014)
- Between 2000 and 2016, worldwide deaths from dementia more than doubled rising from the 14th to the 5th highest rank cause of death (Global Health Estimates, 2018)

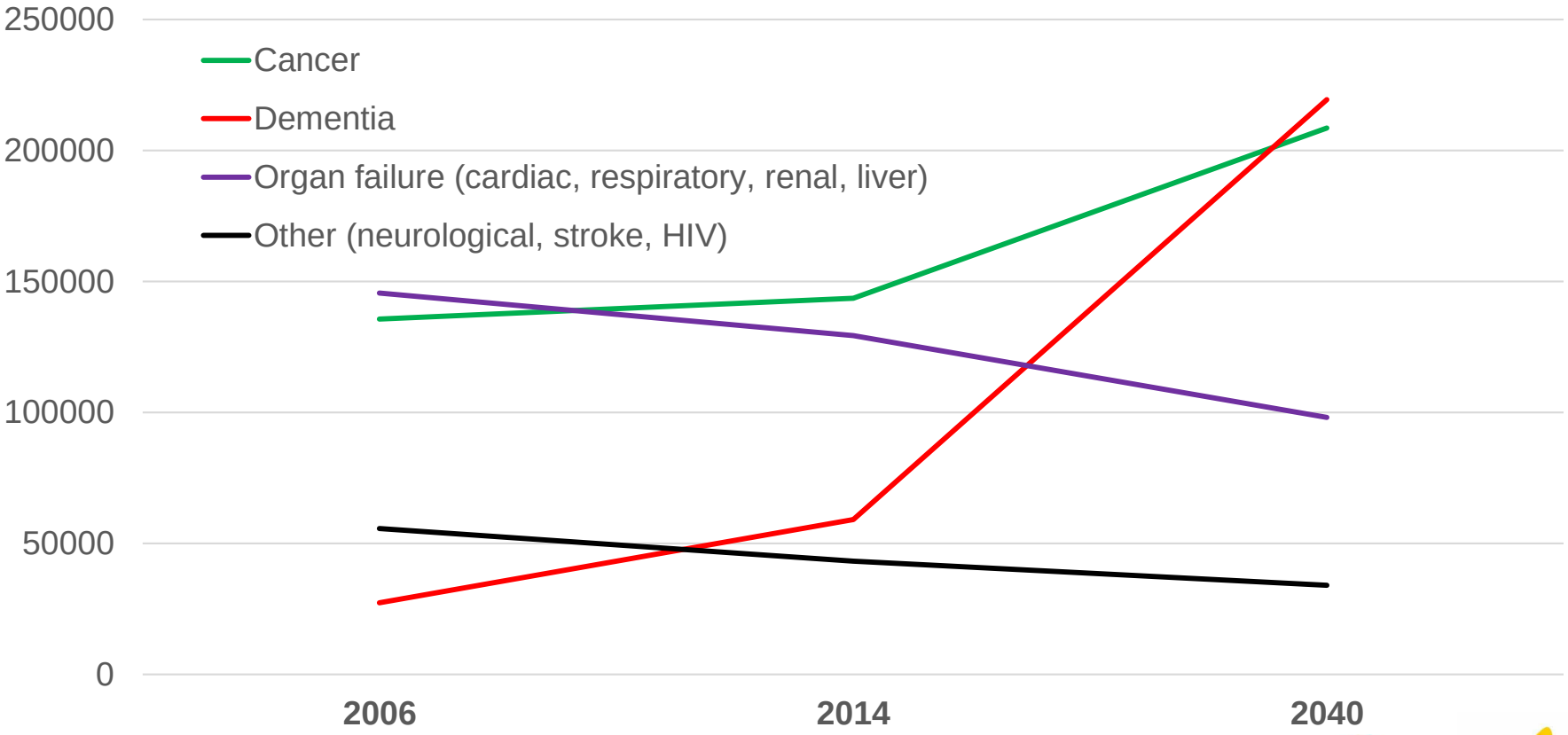
Three ways in which people with dementia die:

1. Mild-advanced stages: People may be in the early stages of dementia and die from another illness (eg cancer, heart disease)

2. More likely in advanced stages: People may die with a number of problems. Dementia may not be the main cause of death but it interacts with other conditions and can reduce capacity to diagnose and treat comorbidities

3. Advanced stages: People may die from complications arising from end-stage dementia (e.g. pneumonia)

Deaths – England and Wales

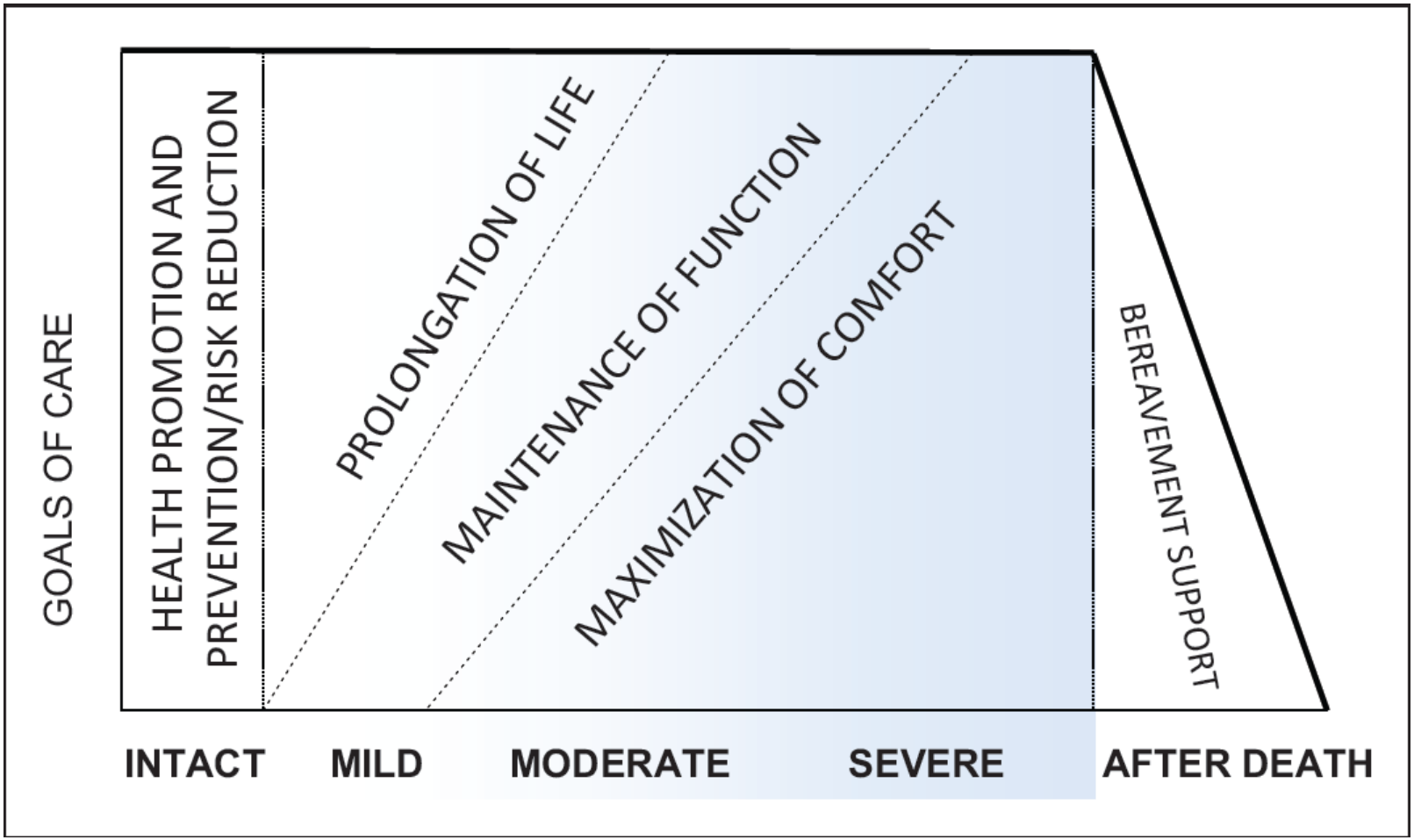


Source: Etkind, S et al (2017).

Challenges of providing end of life dementia care

- Lack of capacity in advanced dementia
- Declines in speech and ability to communicate needs
- Attitudes that dementia is not terminal
- Distress just ‘part of dementia’
- View that dementia is a mental rather than physical condition
- Limited access to healthcare expertise in care homes where the majority of end of life care provided
- Long and uncertain trajectory with comorbidities common
- Carers often feel ill-equipped to be proxy decision makers

Dementia progression and suggested prioritizing of care goals (EAPC White Paper, van der Steen et al 2014, p206)



Understanding clinical needs

- 85 people with advanced dementia over 9 months or until death
- 93% living in a nursing home
- No predictors of end of life
- Characterised by chronicity and uncertainty

Original Article

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Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life

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Alzheimer's Society United Against Dementia

Marie Curie Care and support through terminal illness

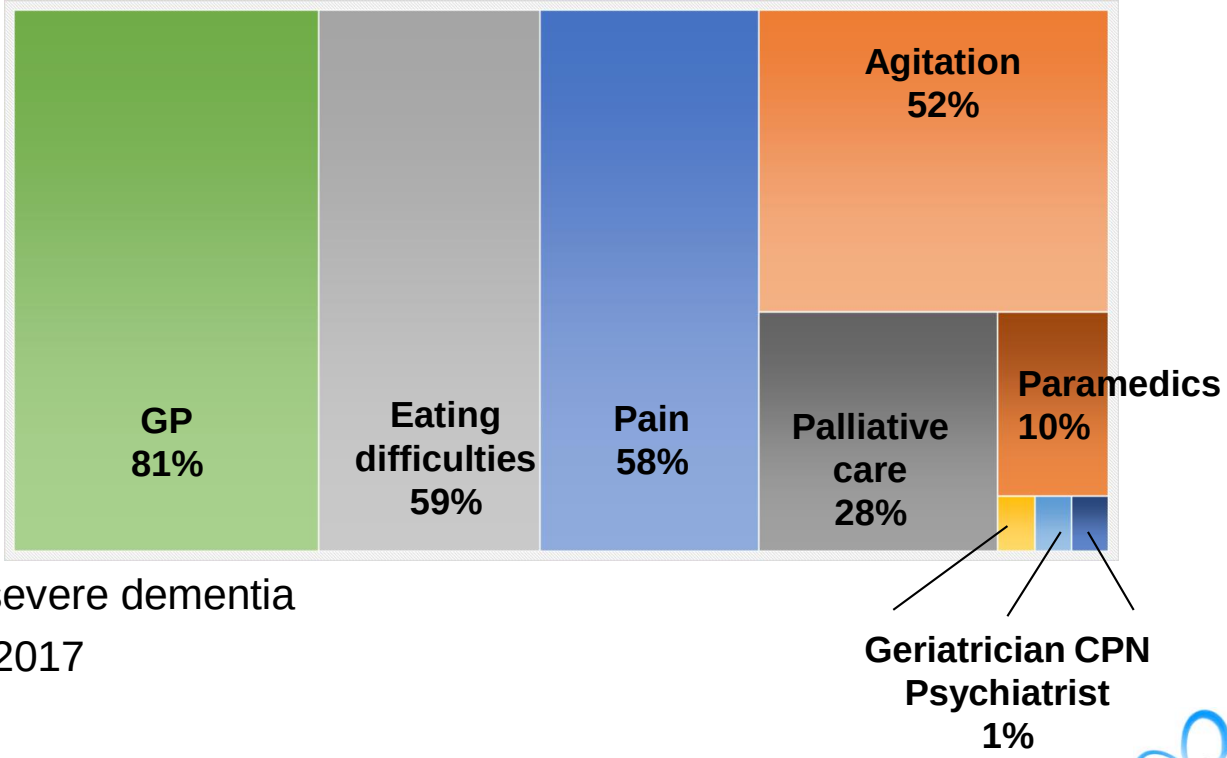
Clinical events and symptoms %

	Study entry (n=85)	Final visit (if alive; n=52)	Final visit (before death; n=31)
PAINAD rest	11	19	13
PAINAD movement	**61**	**60**	**55**
Difficulty swallowing	42	**61**	**57**
Aspirating on swallowing	7	4	20
Weight loss last month	34	46	**53**
Breathing difficulties	19	21	47
UTI	14	10	13
Pneumonia	5	4	17
Septicaemia	1	2	17

Pain in dementia

- Challenging to assess – including observation (eg PAINAD scale)
- Appears to be undertreated but difficult to confirm this
- Significant cause of Behavioural and Psychological Symptoms
- Can lead to inappropriate prescribing of antipsychotic medication instead of pain treatment
- Need to consider medical history and input from family

Symptoms vs. services



85 people with severe dementia

Sampson et al. 2017

Moving away from medical model (Kitwood 1997)

- **Attachment**: a safety net in times of insecurity
- **Comfort**: tenderness, closeness, soothing pain and calming anxiety. Feeling of security.
- **Inclusion**: Need for socialisation – social life of person with dementia often dwindles
- **Identity**: Sense of the past and life story – removing all contact with the past takes away sources of identity; Dementia may erode identity but others can help restore it
- **Occupation**: involved in the process of life in a way that is personally significant and draws on abilities and powers – opposite to boredom, apathy and futility

Behavioural and psychological symptoms of dementia (BPSD)

- Eg: apathy, calling out, aggression, disinhibition, wandering, repetitive actions, depression, anxiety, hallucinations, delusions
- Dementia impairs communication – and ability to express needs
- BPSD is often an expression of an unmet need:
  - **Physical**: pain, infection, fatigue, hunger, functional performance (such as carer possibly overcompensating or restricting independence)
  - **Social**: amount of social contact and the warmth of that contact
  - **Emotional**: boredom, frustration and anxiety
  - **Environment**: light, noise, temperature, over- or under-stimulation

BPSD in cohort (%)

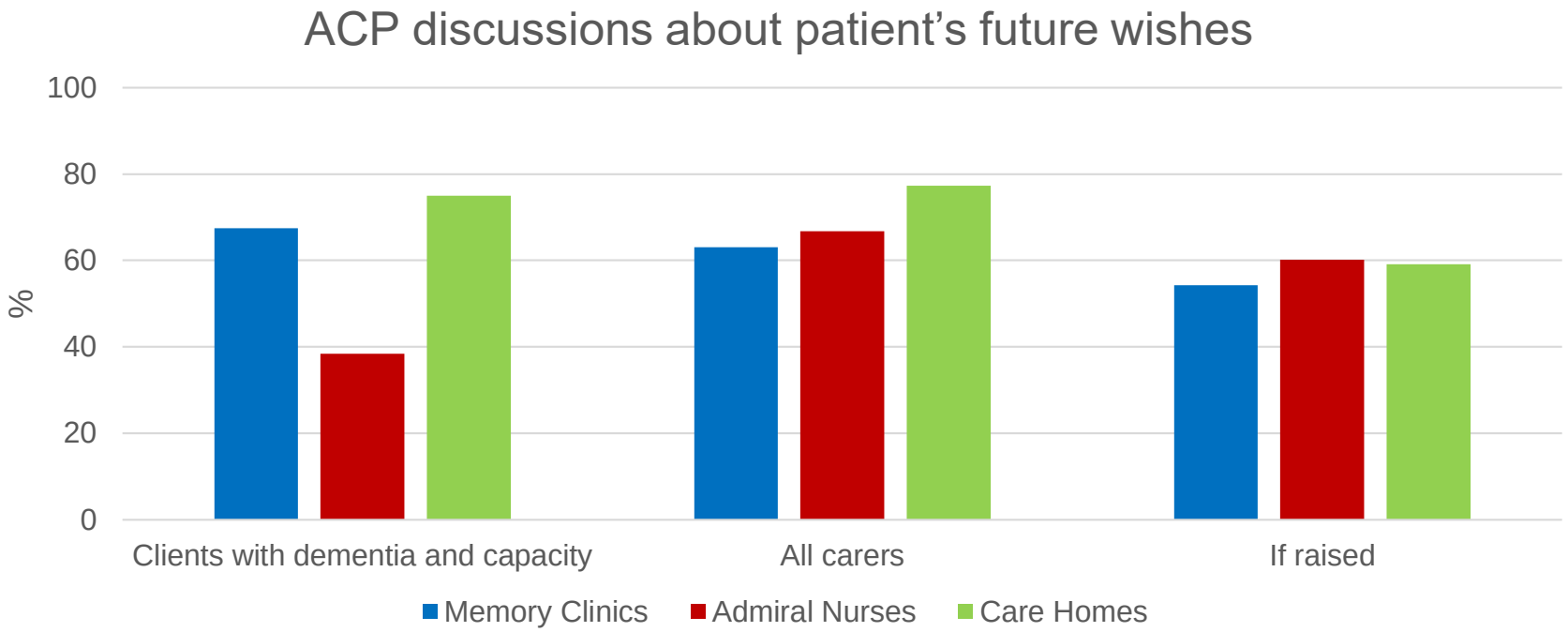
	Study entry (n=85)	Final visit (if alive; n=52)	Final visit (before death; n=31)
CMAI Clinical agitation	**54**	**56**	45
Hallucinations (NPI)	21	27	43
Agitation/aggression (NPI)	**55**	**54**	**51**
Depression	36	42	48
Anxiety (NPI)	35	42	37
Apathy	**53**	**52**	49
Irritability	24	21	43
Motor disturbances	33	48	**50**
Night-time behaviours	44	31	**50**
Appetite and eating	24	38	**61**

Delusions, elation, disinhibition < 20% at all time points
NPI: Neuropsychiatric Inventory

Involving family as partners in care

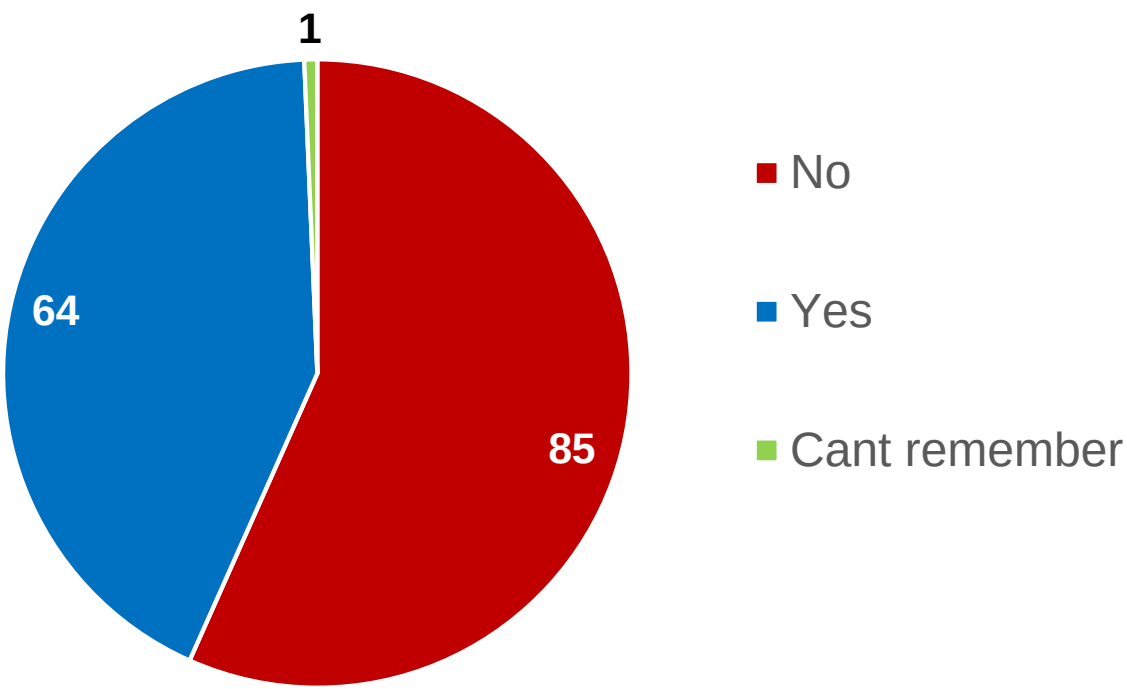
- Provide the bulk of care to people with dementia
- Play a key role in providing person-centred care when communication of person with dementia becomes impaired
- Often best placed to have insight into the goals, values and preferences of the person with dementia > proxy decision maker
- Only 43% of family carers consider dementia a disease you can die from (van der Steen et al 2013)
- A family's perception of dementia as "a disease you can die from" predicts higher patient comfort during dying (rated by nurse) (van der Steen et al 2013)
- Families who understood poor prognosis and clinical complications in advanced dementia – person with dementia less likely to receive burdensome intervention (Mitchell et al, 2009)

UK survey of Memory Clinics, Admiral Nurses and care homes



Moore et al (2019) and in press (care homes and Admiral Nurse survey)

Have HCP's prompted discussions about advance decisions? (150 family carers)



Unpublished, Moore et al

Timing of discussions

Timing	Whether end of life discussions are likely
At diagnosis	• Clinics report this is too early and too much information to take in/not enough time
Weeks/months after diagnosis	• Not all memory clinics have post-diagnostic services to do this • GP probably wont do this
In following years	• No process to trigger conversations • Some services eg Admiral Nursing may have these discussions
Hospitalisation	• If considered end of life may discuss DNAR
Care home admission	• May trigger an ACP process – tick box exercise?

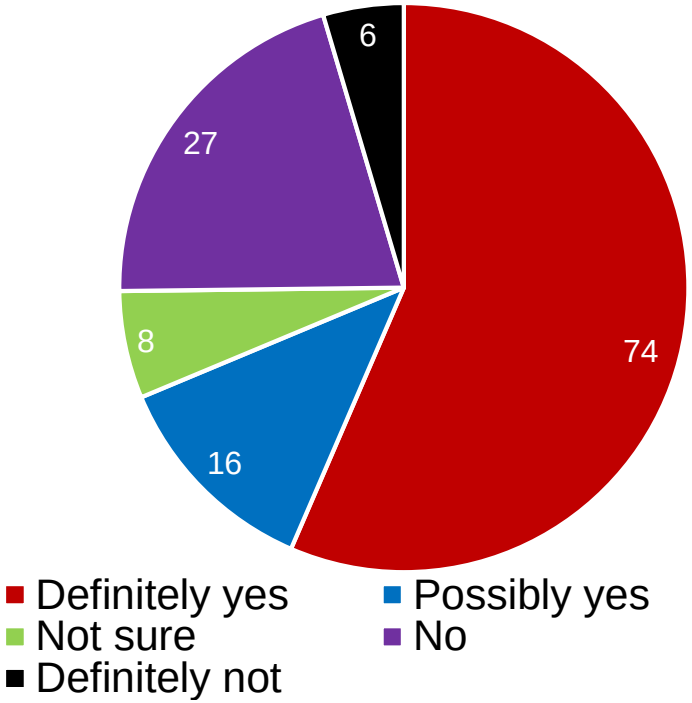
Family carers needing support for own physical and emotional needs

Losses experienced by family and friend carers:

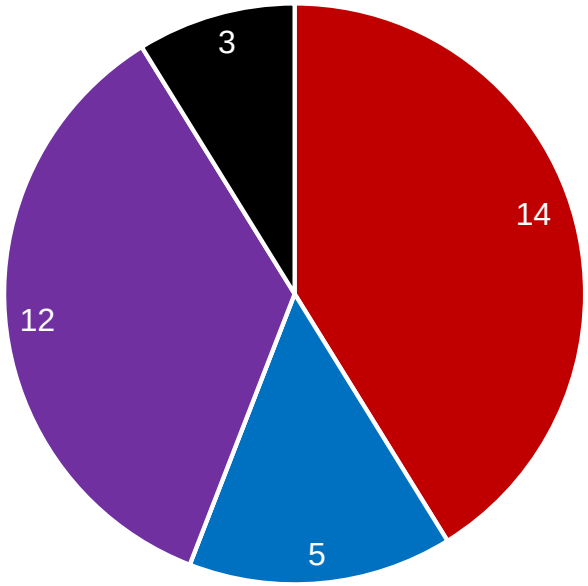
- Relationship: someone to share things with, discuss problems, reminisce, look up to, seek advice
- The person with dementia no longer recognising the carer
- Switch in role from equal or dependent
- Person with dementia moving into a care home
- Personal losses – eg income/employment, social network, time to self
- Death of the person with dementia

Carers identifying as grieving – by gender

Female (n=116)



Male (n=34)



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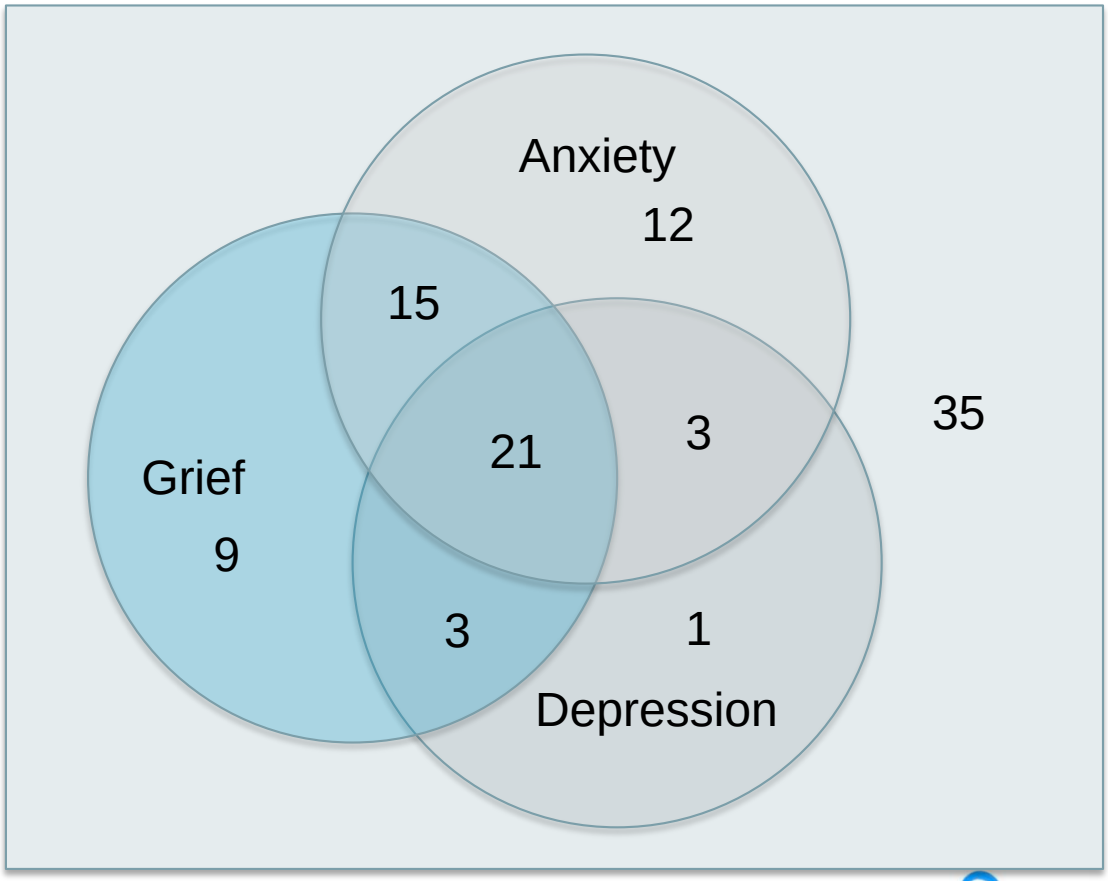
Overlap of depression, anxiety and grief (%) using MMCGI and HADS



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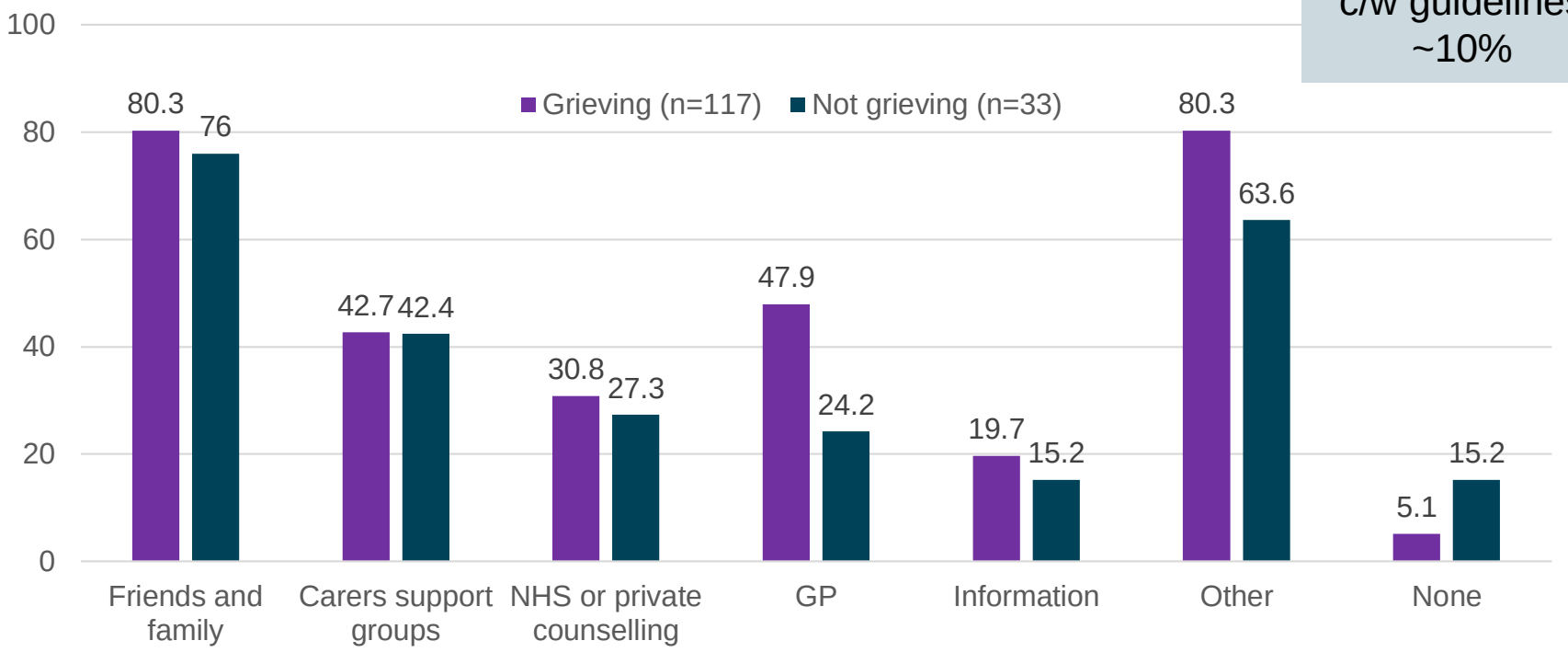
Avenues sought for grief support

55% of all carers sought professional support (GP or counselling), c/w guidelines ~10%



'Other' inc: online forums, carer education sessions, Admiral Nurses

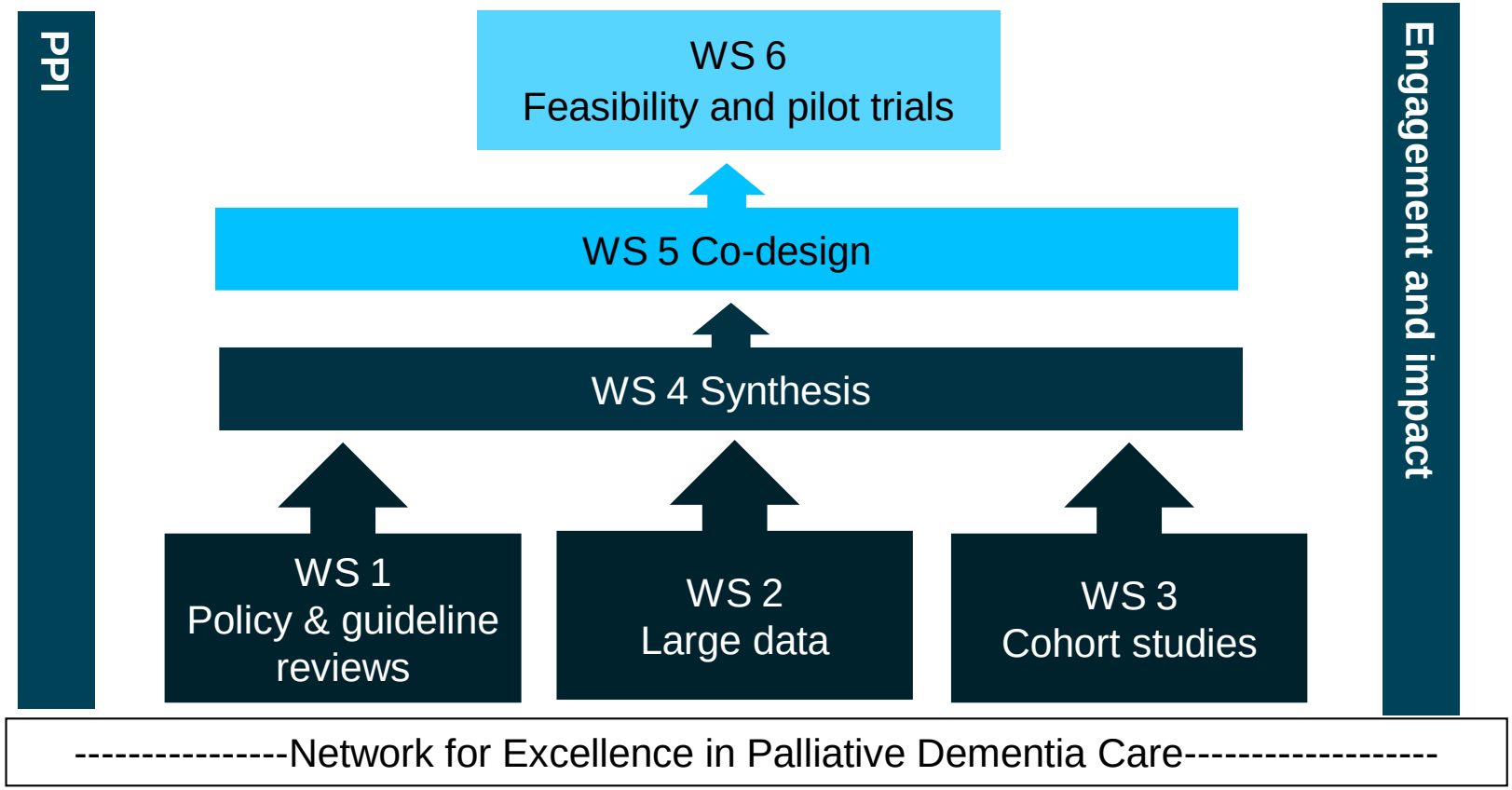
Unpublished, Moore et al

Empowering Better End of Life Dementia Care (EmBED) programme

- 5-year ESCR/NIHR funded programme
- Led by Professor Liz Sampson and Dr Catherine Evans
- Collaboration between Marie Curie Palliative Care Research Dept (UCL) and Cicely Saunders institute (KCL)
- Aims to deliver a step-change in care by developing an innovative model of integrated palliative dementia care, enhancing communication and person-centred decision-making to improve comfort and quality of life

EMBED-Care
Empowering Better End of Life Dementia Care

EmBED Work Streams and structure



EMBED-Care
Empowering Better End of Life Dementia Care

Key messages

- Need to respond to rapidly increasing need for end of life dementia care in coming years
- Care homes and hospitals as most common places for EOL care in dementia – need support from various disciplines
- Meeting needs is complex (loss of capacity and communication)
- Goals throughout dementia care:
  - Person-centred and holistic care that maintains dignity
  - Maintain function and quality of life as long as possible
  - Comfort care and pain management
  - Involving and supporting family carers
- Need for an integrated, multidisciplinary approach with family carers as key collaborators

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Thank you

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