



Mapping the trajectory of the last 12 months of life for people with dementia: the role of specialist palliative care.

Dr Liz Reed, Research Lead, Dr Jennifer Todd, Consultant in Palliative Medicine, Princess Alice Hospice, Esher.

Introduction

Dementia is now one of the top five underlying causes of death. There are concerns about the quality of care and barriers to the provision of quality end of life care for people with dementia (PWD) and their carers.

Method

Retrospective, mixed methods study.
 • Reviewing clinical records of decedent patients
 • Narrative interviews of the carer/next of kin.

2 primary data sources were combined to build the trajectory of the final 12 months. Retrospective level of physical and cognitive ability was estimated at each event by the researcher, using the Functional Assessment Staging Scale (FAST).

Key Findings

- 34 carers approached – 15 consented to being interviewed (44% response).
- 10 of the decedent people with dementia were female and 5 were male, age range was 65–96 (mean 86.5). Relatives interviewed were daughters (6), sons (3), wives (3), husbands (2) and one sister.
- Decedent patients in our study had multiple co-morbidities.

Aim

Map the trajectory of the last 12 months of life. To understand the triggers resulting in a change of healthcare setting and role of Specialist Palliative Care at a local level.

Acute events and crises

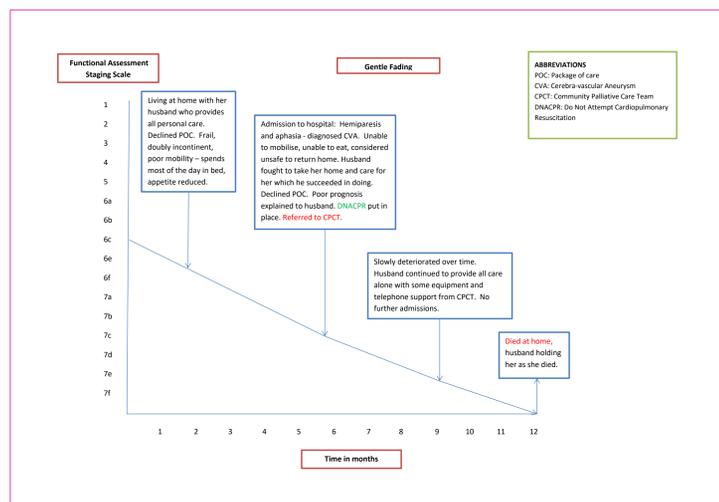
- 14 of the 15 people with dementia had at least one visit to the Accident and Emergency (A&E) department in the last 12 months (range 1–6).
- Reasons for A&E attendance were predominantly falls (13), infection (10), dehydration and constipation (3), and pain (2).
- There were 19 hospital admissions (9 had 1 admission, 5 had 2 admissions).
- On at least 12 occasions, the PWD was discharged directly from A&E.
- Carers talked about the distress they felt and witnessed in the PWD when there was a change in care setting, especially in the acute hospital.



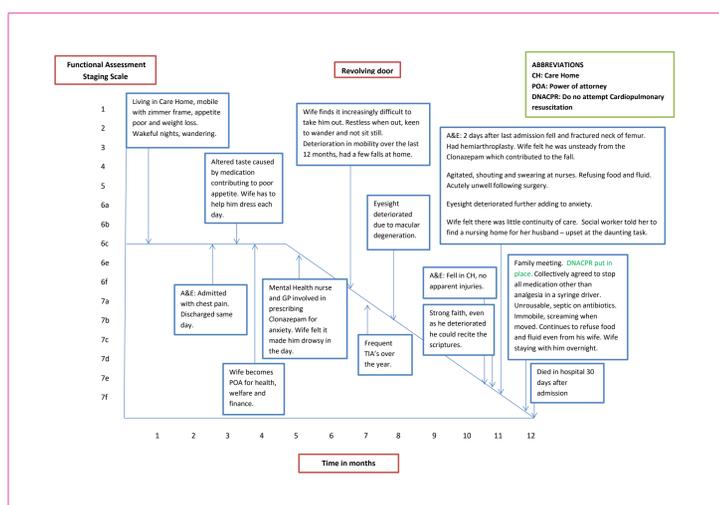
Advance Care Planning

- Only 2 patients in our study had an ACP in place.
- All patients had a DNACPR in place although the majority were only in the last few days of life
- Recognising when someone is entering the final days or hours of life can be particularly difficult in PWD, and in a number of our cases, dying was only recognised very late

2 typical disease trajectories were identified; 'Gentle Fading' and 'Revolving Door'



Gentle Fading trajectory – minimal health or social care intervention required.

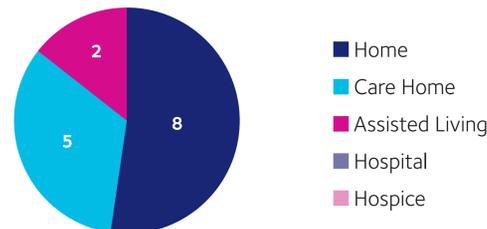


Revolving door trajectory – recurrent acute events and crises with regular attendances at accident and emergency (A&E) and changes in care setting. Two relatives talked about the struggle to get their relative home once they had stepped over the hospital threshold.

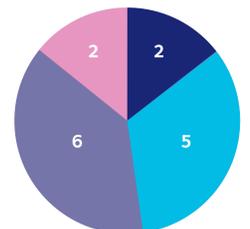
“One day the doctor came, they were always very nice, and said I’m doctor so and so and I’ve come to take some blood... it seems rotten that, doesn’t it, that invasion, when somebody is so near to the end.”

Wife of ID 14

Place of care 12 months prior to death n=15



Place of death n=15



Referral and role of SPC

- 12 of the 15 patients had been referred to SPC
- Median time between referral to SPC and death was 10 days
- SPC interventions
 - non-complex end of life symptom control
 - education and support of care home staff (support with syringe drivers)
 - family support



Conclusion

- There is a need to improve both access to, and duration of specialist palliative care support, in order to provide high quality coordinated compassionate end of life care for PWD and their carers.
- Defining triggers for SPC referral, prognostication and recognition of dying remain challenging.
- Traditional models of SPC need to be adapted to provide a more flexible approach, which fits better with the dementia trajectory for PWD and their carers.
- Promoting ACP discussions earlier in the dementia trajectory with PWD and their carers may help reduce inappropriate hospital attendance.

Implications for practice

SPC has a role in the last 12 months of life for people with dementia but late referral limits the efficacy of SPC intervention. Hospices need to work more collaboratively and creatively with local services to develop skills and models of care that are responsive to the needs of PWD and their carers, in order to reduce the current gap between level of need and services available.

“Every time we were going in there thinking, if we can get out fast enough, we can avoid getting to the next stage. She didn’t feel secure and calm... A&E is not a secure, calm place... it seems like we were stuck in this terrible loop, and I had to be very insistent and co-ordinate all the people to get her signed off and out of there.”

Daughter of ID 12

