



Day Centres: challenges and learning points from a palliative care study

Professor George Kernohan wg.Kernohan@ulster.ac.uk

Dr Felicity Hasson f.hasson@ulster.ac.uk

Dr Shazia Zafar s.zafar@bham.ac.uk

ulster.ac.uk

Three centres: three stages of work

1. existing evidence;
2. existing data;
3. new data



1. What are Palliative Care Day Services (PCDS)?

- Spaces in hospices (even hospitals and community) designed to promote recreational and therapeutic activities amongst palliative care patients.
- Hospices aim to meet the needs of people: physical, emotional, social and spiritual (and religious).
- Including pain control, symptom relief, nursing care, counselling, complementary therapies, spiritual care, art, music, physiotherapy, beauty treatments and bereavement support.



2. FROM THE LITERATURE

...Day services provide professional health and social care to people diagnosed with a life-limiting illness who are living in their own home. Attendance is usually arranged on a weekly basis for a period of weeks, until symptoms ease, or another type of care is arranged.

- a unique environment centred on human interaction;
- a safe place for patients with respite for the carer;
- cross-roads? away from mixed social & clinical, towards specific intervention(s) goal setting with discharge planning;
- role in promoting understanding and acceptance of palliative care

3. FROM 25% OF CHARTS: 82 REVIEWED

We found variation in Palliative Care Day Services across the UK

- ❑ male / female balance; mean. age 73yrs (range 39-94)
- ❑ 87% diagnosed with cancer;
- ❑ 446 issues addressed:
 - physical (74%),
 - psychological (12%),
 - social (10%),
 - spiritual issues (3.1%).
 - 120 reviews of medicines; 79 of equipment
 - 1/3 recorded support to a family member.
- Half had completed an advance or anticipatory care plan.
- Almost 300 onward referrals were made to other health and social care services. Documented wide range of support services that address patient & carer need with service provision heavily influenced by availability.

4. FOCUS GROUP - TALKING TO MANAGERS & STAFF x 3

Palliative care day centres: qualitative study with multi-disciplinary team demonstrates need for standardisation

- Day hospice is unstandardized with regards to staff mix, services and structure with referral (and the timing of referral) and dependent upon external gatekeepers, following ad-hoc development.
- Services are importance to patients and family caregivers, valued by staff, but a certain stereotype prevails upon the services offered and who uses them;
- Emphasis upon economic viability & VFM, but hampered by the use of management metrics & lack of 'proper' outcome data.

5. Let's celebrate PCDS strengths

Physical &
psychosocial
support

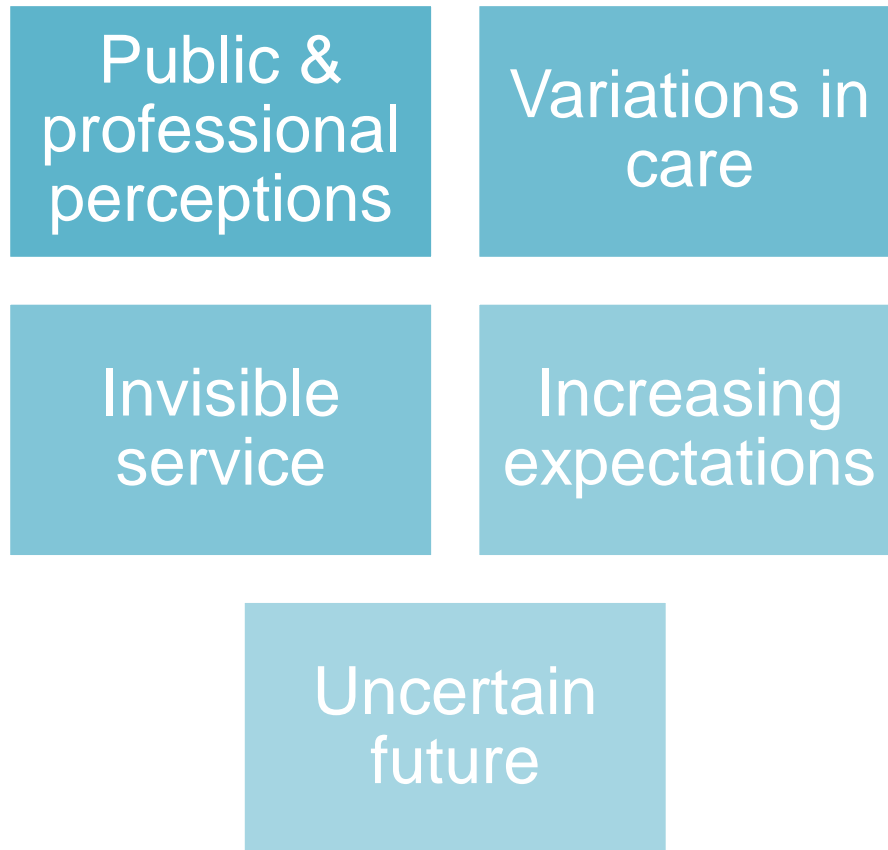
Access to
specialist staff

Respite care

Allay fears

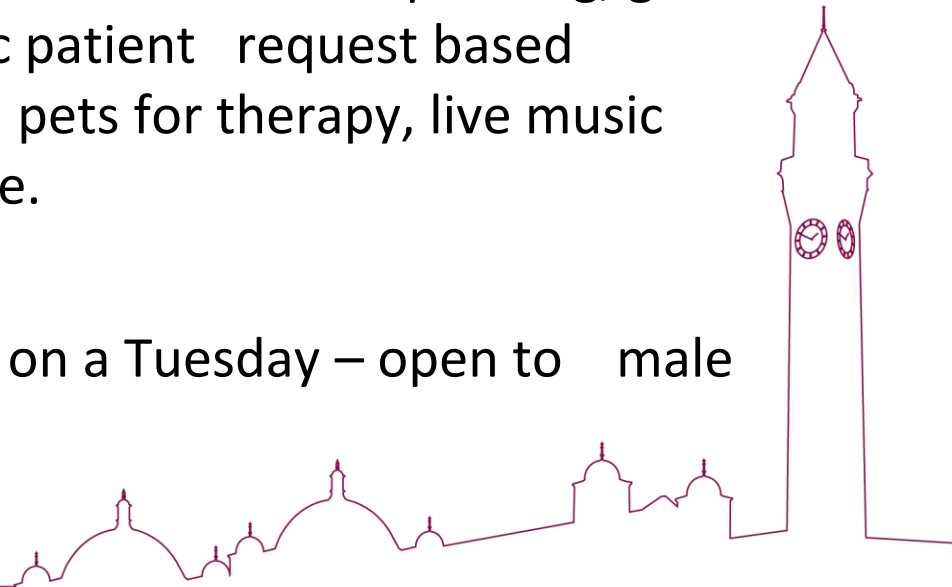
Signposting &
access

6. Key challenges



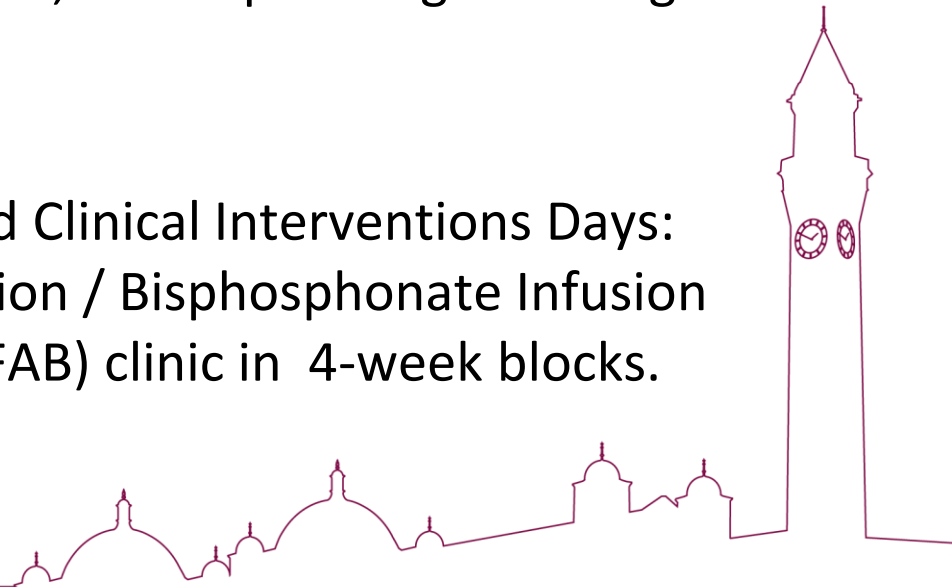
7. Case Study West Midlands - Day Services at Marie Curie Hospice

- Day services in 2017 operated on a Monday, Tuesday and Thursday.
- Criteria for admission: *anybody with a palliative care diagnosis with complex needs and symptom control issues.*
- Social Day (Tuesdays) – need for social involvement or who become isolated. Activities include arts & crafts such as silk painting, glass painting, card making; with ad hoc patient request based activities: cookery demonstration, pets for therapy, live music sessions, quizzes, morning exercise.
- Men's Shed group also took place on a Tuesday – open to male patients attending social day.



8. Case Study West Midlands - Day Services at Marie Curie Hospice cont'd

- Wellbeing Day (Monday and Thursdays) – devised by Day Services Sister and communicated to MDT staff who managed the activities in Day Services.
Programme: breathlessness talks, nutritional talks with cookery, anxiety and fatigue management, look good feel good sessions (make up and nail varnish), falls prevention, future planning including advanced care planning.
- Wednesdays and Fridays remained Clinical Interventions Days:
Wed - provision of Blood Transfusion / Bisphosphonate Infusion
and Fri – Fatigue Anxiety Breath (FAB) clinic in 4-week blocks.



9. Cohort Study 2017 - 2018

1. Recruiting patients and their close persons referred to Day Services for face-to-face interviews: (1hr, at 3 times points 4-weeks apart over 3 months i.e. 12 weeks of their Day Services journey).

2. Eight tools used to assess patients' and carers' experiences and health status:

- POS-S (Palliative Care Outcome Scale – Symptoms).
- PHQ-2 (Patient Health Questionnaire 2).
- MQOL-E (McGill Quality of Life – Questionnaire Expanded).
- EQ-5D-5L (Health Questionnaire).
- ICECAP-SCM (Supportive Care Measure).
- CSRI (Client Service Receipt Inventory)
- QOLLI-F v2 (Quality of Life During Serious Illness Family Care Giver Version)
- ICECAP-CPM (Close Person Measure)



10. Cohort Study 2018 Data from the 3 sites:

Cohort Study 2018	No of PATIENTS	No of CLOSE PERSONS
West Midlands	31	10
Belfast	16	10
Edinburgh	9	5
TOTAL	56	25

Cohort Study 2018	No of PATIENTS at Baseline	No of PATIENTS at 4 weeks	No of PATIENTS at 8 weeks	No of PATIENTS at 12 weeks	No of CLOSE PERSONS at Baseline	No of CLOSE PERSONS at 4 weeks	No of CLOSE PERSONS at 8 weeks	No of CLOSE PERSONS at 12 weeks
West Midlands	31	22	18	9	8	5	3	3
Belfast	16	8	6	1	9	4	3	1
Edinburgh	9	8	7	6	5	5	4	5
TOTAL	56	38	31	16	22	14	10	9



11. Cohort Study 2017 – 2018

Data from West Midlands:

WM PATIENTS Cohort Study 2018		Comments
Number recruited, n =	31	
Completed 12 Weeks	9	
Completed 8 Weeks	9	
Completed 4 Weeks	5	2 from FAB – 4 week programme,
		2 became ill and hospitalised,
		1 removed from study because no further attendance.
Completed 1 Week	8	1 died,
		2 removed from study because of no attendance,
		4 became ill and hospitalised,
		2 removed from study because of request from the patients.

CLOSE PERSONS (CP) Cohort Study 2018		Comments
Number recruited 10, but assessment from 8, n =	8	
Completed 12 Weeks	3	
Completed 8 Weeks	0	All completed to 12 weeks therefore 0.
Completed 4 Weeks	2	2 not returned any of my calls / communication with patient beyond the week 4 assessment.
Completed 1 Week	3	1 died, 2 not returned any of my calls / communication with patient beyond the baseline assessment.
CP refused after recruiting	2	2 not returned any of my calls / communication with patient.
CP with no communication	6	No communication from 6 CPs when chased up.
CP declared by patients, n= 16 (inc 10 recruited).		General reason given by patient is that their CP is too busy.

12. Comparison of Cohort Study 2018 with Mapping Study 2015

Mapping Study 2015	Belfast (n=36)	West Midlands (n=24)	Edinburgh (n=22)
Age			
Mean	72.4 years	71.6 years	76.0 years
SD	11.0	14.3	10.5
Range	46-86 years	39-93	56-94 years
Gender			
Male	19 (52.8%)	13 (54.2%)	12 (54.5%)
Female	17 (47.2%)	11 (45.8%)	10 (45.5%)

Cohort Study 2018	Belfast (n = 16)	West Midlands (n = 31)	Edinburgh (n = 9)
Age			
Mean	66 years	70.0 Years	75 years
SD		12.4	
Range	57 - 81 years	41 - 98 years	51 - 91 years
Gender			
Male		14 (45.16%)	
Female		17 (54.84%)	



13. Staff Profile within Cohort Study 2018 5

Cohort Study 2018	Belfast	West Midlands	Edinburgh
Staff (Proportion of FTE)			
Manager - social worker		1	
Manager - nurse	1		
Manager - allied health professional			0.6
Associate Specialist Doctor	0.4		
Nurse consultant	0.2		
Social worker	0.6		
Palliative care nurse		1	
Occupational therapist	1	0.2	0.6
Physiotherapist	1	0.2	
Registered nurse	1	1	0.6
Rehabilitation assistant			0.6
Health Care Assistant	1		
Secretary	1		
Volunteers (Proportion of FTE)			
Complementary therapists	2	0.4	0.2
Drivers	3	2.4	3.6
Hospitality	3	2.8	1.8
Hairdresser			0.25



14. Other issues creating challenges

- Gatekeepers
- Recruiting on to study by phone
- Meeting with patients
- Meeting with close persons (traumatised)
 - i. Health Professionals
 - ii. Difficult Scenarios / Uncooperation
- Other day services programmes – FAB
- Very upsetting questions for patients and cp
- Rude patients and some racism – becomes a barrier
- Bewildered patients – recent diagnosis



15. FROM A COHORT STUDY, WE WERE ABLE....

Explore the costs, consequences and efficiency of three types of Palliative Care Day Services

- 38 cases with follow-up data at four weeks (8; 8; 22).
- cost per attendee/day £121-£190 (excluding volunteers);
- to £172-£264 (including volunteer contribution)
- Other health and care costs (+ £570, -£1,127, + £65);
- MQOL-E (centre 1: -0.48, centre 2: 0.01, centre 3: 0.24);
- EQ-5D-5L (centre 1: 0.05, centre 2: 0.03, centre 3: -0.03)
- ICECAP-SCM (centre 1:0.00, centre 2: -0.01, centre 3: 0.03).
- Efficiency is influenced by occupancy rates
- large contribution made by volunteers
- weak evidence of clinical outcomes, or reduced costs

16. We conclude that palliative care day services

- Provide a unique safe place for people that is responsive to needs!
 - Need referral criteria & standardisation!
 - Document many physical issues as being addressed!
 - Can be supported by volunteers!
 - Need studied by quasi-experiment, to add evidence!



THANK YOU!

QUESTIONS ??

Professor George Kernohan wg.Kernohan@ulster.ac.uk

Dr Felicity Hasson f.hasson@ulster.ac.uk

Dr Shazia Zafar s.zafar@bham.ac.uk

ulster.ac.uk