

Capturing the end of life experience:

A method to improve case-studies to identify unmet need



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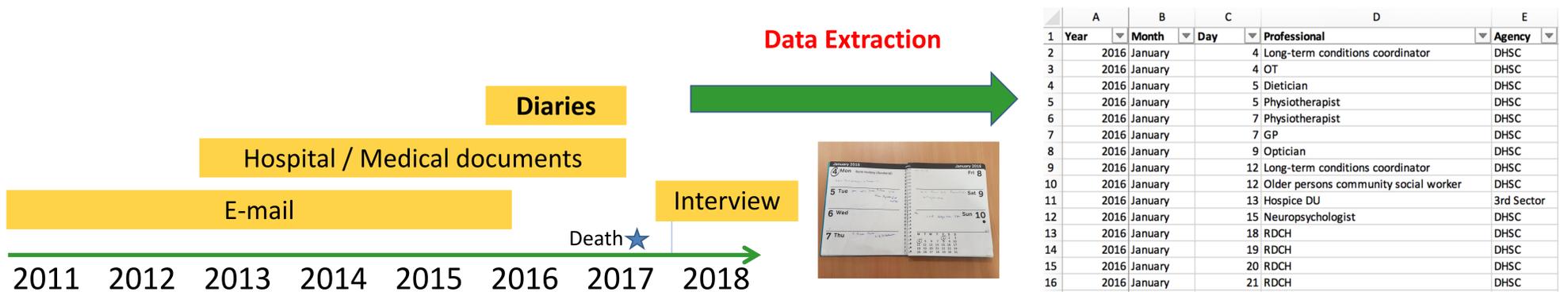
Background

- ❖ To deliver person-centred and integrated end of life care, providers need to understand the experience of patients and carers.
- ❖ Real-time experience may differ from retrospective accounts which may have implications for initiatives to improve care.

Aim: To explore the benefits of using a combination of prospective and retrospective data collection methods from multiple sources to understand the experience of care from the perspective of a patient and carer.

Methods

- ❖ The spouse and carer of a patient with progressive supranuclear palsy (PSP) was approached 6 months after death for an interview.
- ❖ Using personal diaries, face-to-face contacts with providers during the last 18 months of life were extracted and coded for analysis.
- ❖ Timeline from pre-diagnosis to after death was created using details provided by the carer and verified by correspondence and medical care documents kept by the patient/carer.



Analysis

- ❖ Each professional who provided care during this period was graphically represented by job role or agency (Figure 1).
- ❖ Number of contacts were plotted by provider of care (DHSC, 3rd Sector or private) for the 18 month period before death (Figure 2).
- ❖ Using the Case Study materials as a tool for discussion, gaps in end of life care provision in the Isle of Man were identified in a workshop held in December 2017 including professionals from DHSC, Hospice and the Council of Voluntary Organisations.

Results

Timeline

2011	• Early symptoms: Vision problems, arthritis, starting to lose muscle control, slower movements and frequent falls (not reported). Referral to Rheumatologist.
Dec. 2013	• Increased problems with mobility, distress, anxiety, disability and dependence. Continued deterioration as noticed by family not explained by arthritis.
July 2014	• Family suspects Parkinson's Disease (PD) and discuss with GP. Referred to Neurologist who makes expected/probable diagnosis of PD.
Aug. 2014 to 2015	• Parkinson's nurse becomes involved; physiotherapy, OT services, Independent Living Centre provide input. Minimal improvement made with medication. More falls and recurrent UTI's. A&E visit after a fall – 4 stitches in eyebrow & 2 broken metacarpals. Carer fully responsible for all household chores due to increased disability.
Aug. 2015	• Diagnosis changed to Progressive Supranuclear Palsy (PSP).
Nov. 2015	• Long-term Conditions Coordinator appointed and takes over care coordination. Family decides to move to the Isle of Man to assist with care.
Dec. 2015	• Ambulance called and admitted to Hospital due to blood infection and UTI. Fractured pelvis discovered upon examination. GP referral to Hospice.
Jan 2016 to Feb 2017	• Carer gradually overwhelmed. Periodic one or two week in-patient respite (DHSC). Third Sector begins to provide respite support. Private care agency contracted for help with showers. Catheterisation. Regular visits from District Nursing (DN) team.
March 2017	• Private nurse hired at the start of March for night care and help at bed time. Increased difficulty with symptom management – severity of spasms and pain increasing. Multidisciplinary Team meeting held with family.
April 2017	• Private domiciliary care during daytime. Increased use of private night nursing staff. April 29 (Friday evening) – unable to control pain with medications available at home or any telephone advice from emergency doctor service (MEDS). Private nurse and family take patient to MEDS clinic for pain medication. Sent home with oral morphine. Family and private nurse care for patient until admitted to Hospice on May 1 st for previously scheduled respite.
May 1 to June 3 2017	• Patient cared for in Hospice Inpatient Unit until her death on June 3, 2017. Carer very relieved and reassured once patient was admitted.
June to Dec. 2017	• Administrative tasks completed by carer. Long-term coordinator arranges for equipment removal and monitors carer. Post-bereavement support offered to carer.

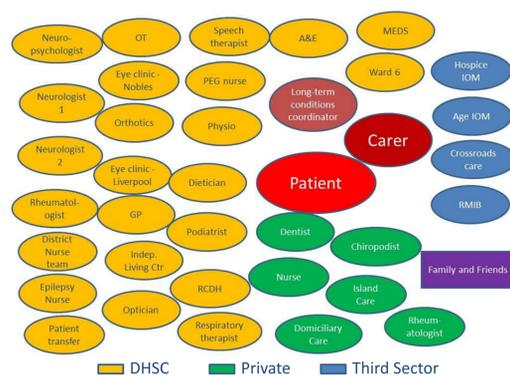


Figure 1. Ecosystem of care for a PSP patient

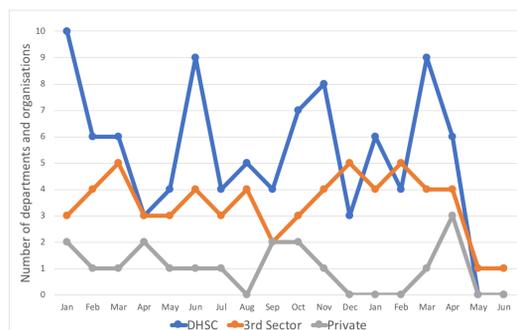


Figure 2. Number of encounters per month by sector in the last 18 months of life of a PSP patient

Identified gaps

Pre-diagnosis to diagnosis (2011-15)

- ❖ Identifying complex cases
- ❖ Triggers for signposting to community support
- ❖ Self-management programme

Increasing complexity and disability

- ❖ Care navigation – all sectors
- ❖ IV antibiotics at home
- ❖ Emotional wellbeing and respite
- ❖ Anticipatory care planning
- ❖ Carer support

Last year of life

- ❖ Out of hours service availability
- ❖ Review of preferred place of care

Conclusions

- ❖ The method of constructing the case study provides a whole system account of care, as experienced by the patient and carer.
- ❖ A combined approach to data collection is a promising method to capture user experience to inform service design and delivery.
- ❖ Further studies in different conditions are planned.