

Title:

Using Experience-based Co-design with family carers of individuals living with Dementia and healthcare staff to improve experiences of attending the Emergency Department

Supervisory Team:

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Aim:

To use Experience-based Co-Design (EBCD) to identify concerns and solutions to improve the experiences of individuals living with dementia and their family carers attending the Emergency Department (ED) from a Nursing Home or own home.

Objectives:

1. To investigate the experiences and perceptions of individuals living with dementia (with cognitive ability), and their family carers on attending the ED
2. To investigate the experiences and perceptions of ED staff in providing care and support for individuals living with dementia and their family carers attending the ED
3. To identify improvement priorities and solutions for ED based dementia services through co-design

Background:

Dementia is a term representing a range of brain disorders that affect cognitive reasoning and the capability to function independently¹. It is progressive and palliative, significantly affecting the quality of life of the individual living with dementia but also their family carers². With improved healthcare standards and increasing longevity the number of people living with dementia is increasing, a figure was estimated at 47million in 2015 and projected to double every 20years; in Northern Ireland the figure is approximately 19,000, predicted to rise to 60,000 by 2051^{3,4}. Therefore, a large proportion of global society will be affected by either having dementia themselves, or by providing informal care. In the United Kingdom almost half of unplanned hospital admissions of people over 70 years old have dementia⁵. Attending the Emergency Department (ED) can be a very stressful and disorientating experience for an individual living with dementia, extending stress to their family carers and can also be very challenging for ED staff, due to the complexity of their health profiles^{6,7}. For individuals living with dementia attending an ED and for acute care can lead to further cognitive and physical deterioration, nonetheless ED attendance remains common, with some studies showing an increase in attendance increasing at end-of-life^{8,9,10}.

An approach not previously implemented is collaborative working between family carers of individuals living with dementia, the individual with dementia (with cognitive ability), and healthcare staff in designing ED based dementia services. This would allow investigation of the needs and experiences of family carers, patients and ED staff to inform quality improvement endeavours.

Methods:

EBCD is a form of participatory action research that endeavours to gather and understand how individuals actually experience a process or a service^{11,12}. Through the EBCD process experiential narrative data will be collected utilizing audio and filmed individual interviews, with ED staff and family carers/patients respectively. This will identify and explore the emotional key moments on the care journey for the individual living with dementia and their family carer, and of the experience of ED staff in providing care and support, with a view to improving these experiences. Non-participant observation will also be conducted within the ED recording field notes of the family carer/patients' experiences focusing on functional and relational aspects of carer/patient/staff interactions, helping to contextualise and understand experiences from all perspectives. A facilitated co-design event will then allow feedback and discussion of the findings, enabling staff to highlight their priorities for carer support provision and allowing family carers/patients to reflect on the emotional impact of key experiences. In collaboration, all participants will select shared improvement priorities and together redesign relevant elements of the ED service to improve the identified areas.

Timeline & Key tasks:

- Year 1. Systematic review – “Experiences of carers and individuals living with dementia attending the Emergency Department”
Ethics application preparation and submission
- Year 2. Data collection and analysis
- Year 3. Thesis write-up

Study Timeline

ACTIVITY	YEAR 1	YEAR 2	YEAR 3
Systematic review	■ ■ ■ ■ ■		
Protocol development	■ ■ ■ ■ ■		
Ethics application and submission	■ ■ ■ ■ ■		
Data collection & analysis			
EBCD Stage 1 – Staff interviews, non-participant observation, family carer/patient interviews		■ ■ ■ ■ ■	
EBCD Stage 2 – staff feedback		■ ■ ■ ■ ■	
EBCD Stage 3 – family carer/patient feedback		■ ■ ■ ■ ■	
EBCD stage 4 – co-design event		■ ■ ■ ■ ■	
EBCD stage 5- co-design working groups		■ ■ ■ ■ ■	
Thesis write-up			■ ■ ■ ■ ■

References:

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