Key findings

Sixteen participants (aged from 70 to 90 years old) with dementia took part in the study. Almost all participants had multi-morbidities, e.g. diabetes, COPD, heart conditions, chronic pain, suspected cancer, sensory impairments. The participants varied in gender, age, relationships to carers, types of dementia and co-morbidities. Eight carers joined in the interviews. Three key themes emerged:

i) The meaning of enablement in later life

Despite increasing frailty, many people with dementia (PwD) talked about the meaning of enablement. The concept of enablement was associated with the maintenance of a sense of the continuing self and agency in daily situations. Sub-themes include: being self-reliant, adjusting to changes in life, having a meaningful routine with purpose and enhancing interdependency.

ii) Enablement Services (ES) as instrumental to support transitions in daily life

Many PwD perceived ES as instrumental to: a) support them in transition to their ‘usual’ daily routine at home; and b) offer support to alleviate burden and strain on their family. However, some carers were sceptical that PwD had been ‘sent’ home with the ES inappropriately without sufficient assessments and resources in place.

iii) Enablement through activity engagement in everyday life

Many PwD valued the opportunity to be re-engaged in their daily activities through a range of approaches offered by the ES, for example, re-learning skills and routine in daily life, re-gaining functional mobility, receiving home adaptation and equipment to support daily activities, accepting changes and undertaking social interaction. However, their level of engagement with the services was often affected by how the staff related to them during their visits. These factors included, for example, respecting their value, taking time to build a relationship and to listen and communicate with them.

Background

Dementia is a public health priority. It is one of the main causes of disability and dependency later in life (NICE 2015). Two-thirds of PwD live at home, cared for by family. Many are supported by homecare services which are provided and commissioned by Local Authorities (United Kingdom Homecare Association 2015). This situation presents challenges to social care systems in supporting PwD’s ability to live an active and healthy life at home due to the increasing complexity and scope of PwD’s care needs and support in later life, and funding cuts to adult social care in the face of austerity (Care Quality Commission 2017). Homecare Enablement services (ES) aim to enable adult service users’ independency including PwD through a person-centred method, within a timeframe. However, the term ‘Enablement’ is not well defined and there is no consensus on how enablement could be achieved (Cochrane et al 2016). ES are delivered using different methods, depending on local commissioning decisions and models of health and social care services. The role of occupational therapists is recognised as crucial in the implementation of ES (DH 2014). Evidence of the effect of the ES on PwD is limited (Cochrane et. al 2016, Poulos et al 2017). If ES are to be effective, there is a need for a clear understanding of users’ views, needs and preference (Dawson et al 2015) as such information is crucial to inform service commissioning for Enablement Services (King’s Fund & Nuffield Trust 2012). Moreover, there is an increasing recognition that, if community-based care is to be effectively delivered, the need to listen to the voice of PwD is critical (NHS England 2019).
Methodology
Following research governance and University ethical approval, participants with a confirmed and suspected (being investigated) diagnosis of dementia were invited to take part in two semi-structured interviews via nine Homecare Enablement teams within a local authority. Family carers joined in the interviews with participants’ consent. All participants lived at home and had recently been supported by the Enablement teams with specialist occupational therapist oversight and assessment in each team. Initial interviews focused on PwDs’ narratives of the impact of the ES on their daily functioning. Overall findings were taken back to the participants at the follow-up interviews for member-checking. All interviews were digitally-recorded and transcribed verbatim. Each transcript was read, re-read and coded to develop concepts using the constant comparison method of a grounded theory approach. Rigour was maintained using criteria such as credibility, reflexivity, attention to power relationships, member-checking and trustworthiness (Charmaz 2006).

Conclusion and Recommendation
Older people with dementia are vulnerable due to memory decline and chronic/acute illnesses, and have complex activities of daily living needs. They have a desire to continue engaging in meaningful activities and to use their remaining abilities. Free short-term Homecare Enablement Services have the potential to support individuals at crucial life transitions within the dementia pathway, promoting their wellbeing at home. This study supported the NICE guidelines (NICE 2017), highlighting the need for staff within enablement services to work across organisations in order to coordinate review and reassessment. Occupational therapists, with the knowledge and skills in personalised complex intervention, play a key role in the on-going development and implementation of the Homecare Enablement Services. However, the unique role of occupational therapists in supporting PwD within ES teams is not well understood by the service users. The nature of ES is evolving to meet the requirements of Care Act 2014. Service improvements and design must take into consideration the experiences and viewpoints of PwD. Moreover, this research highlights a need for further research into the impact of the ES on PwD from the perspective of frontline staff, including occupational therapists, as they play a key role in engaging PwD in the enablement process.

Publications (conference presentations)
Chung P (2018) The Perspectives of People Living with Dementia on Enablement Services at home, WFOT Congress, Cape Town, South Africa

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