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Phd Title: To what extent are Person Centered Care Principles, Choice and Inclusion evidenced in the assessment and decision making process for placement in permanent Residential Care for those living with Dementia in England.

Study Route: Part Time Study.

Supervisory team: Professor Claire Surr and Dr Sarah Burden

Background: Dementia is a growing issue both globally and in the United Kingdom (UK) (Alzheimer's Disease International, 2015) and age is the biggest single risk factor for developing dementia (Alzheimer's Research UK, 2014). In the UK we have a progressively aging population, with estimations that by 2034, 23% of the population in the UK will be over the age of 65 years (Office of National Statistics, 2016). Of these people it is predicted that by 2020, 1 million will be living with dementia and by 2051 this is set to rise to 2 million (Alzheimer's Society, 2014). The disease trajectory is somewhat different for each person but it is likely that at some point in their journey with dementia, people will need formal care to assist with daily living needs and for many this will progress to needing 24hr care (Geibel et al., 2015). The overall care costs associated with dementia are growing rapidly with predictions that these will reach £59.4 Billion per year by 2050 (Alzheimer's Research, UK 2014). A major contribution to the care costs is the provision of long term residential and nursing care. At any one time, one third of people with a formal diagnosis of dementia will be residing in permanent care homes, albeit Nursing or Residential Care (Alzheimer's Society, 2014).

In 2013 England had 12,848 residential homes registered with the Care Quality Commission, along with 4664 registered Nursing Homes. The number of nursing home beds was 218,678 and the number of residential care beds was 244,232 (Care Quality Commission, 2013/14). Alzheimer's Society (2013) report that as many as 80% of people residing in care homes have dementia or significant memory loss, but less than 2 in 5 of these people will have a formal diagnosis. This means that there could be as many as 300,000 people living with dementia in care homes in England (Alzheimer's Society, 2013).

The point at which someone enters into permanent care is varied and the individual need for permanent care is based on very complex situations and needs. However, literature indicates that the majority have a 3-4-year period between diagnosis and admission into long term care (Brodaty et al., 2013).

Majority of people with complex needs who are deemed to potentially no longer be cared for at home, will undergo an assessment by a Social Care Practitioner and this assessment is then scrutinised by a decision making panel (which may not include the assessor). A decision about the type of care package they need (enhanced care package in the home, residential/nursing care placement) and funding for the placement is then made based on the assessment details. This includes an assessment of the person's financial situation against thresholds for receipt of local authority funding, and their care needs against the threshold for receipt of NHS continuing care funding for those with specific nursing care needs. A further complexity of the current situation is that if clients are self-funding they may not need an assessment by the Local Authority and may choose to facilitate their own admission. However, if a client requires support to source an appropriate home or help with funding until their capital is released, then they will still require a full assessment by their local authority, and a panel will decide if they will be granted funding. Thus the assessment processes and pathways from care in one's own home into residential or nursing care are complex.

In the UK there are national best practice guidelines for the assessment and treatment options for those living with dementia (Royal Collage of Nursing, 2013; NHS England, 2015; Alzheimer's Society, 2017 and NICE, 2016 and 2017). These all recommend the inclusion of client and carer choice and preference regarding treatment options, including when and where they are permanently placed. These recommendations are also reiterated by NICE (2017), who in their Dementia Pathway Guideline advocate that when making decisions about care, the choices of the person living with dementia and their carers should be included in all aspects of decision making.

The assessment process is vital to ensuring that the person with dementia has an appropriate placement that meets their needs and preferences. However, Local Authorities across the UK have different assessment processes and indeed care pathways for dementia. Health Education England (2017) provides on-line dementia roadmaps, which give information regarding processes, facilities and support networks within various geographical areas. These roadmaps and pathways vary greatly between geographical areas, as do the processes for assessment and diagnosis. This means that the process for assessment and admission to permanent care is different across the country and concerns have already been raised about the inconsistency and varied quality of care given during the transition period (Care Quality Commission, 2014).

## **The aims and objectives of the PhD**

- To conduct a scoping review to determine what research has been completed in the area of inclusion, choice and PCCP in the assessment for admission into residential care. This will identify the existing gaps in the literature, and identify existing recommendations for further research.
- To understand how person centered principles and best practice guidelines are applied within the assessment process, for someone living with dementia and their carer.
- To understand how person-centred principles, inclusion and choice are accommodated in the decision-making for admission from home to a permanent residential care.

## **Your study design and methods**

The literature review will focus on literature pertaining to the assessment and transition phase from home or hospital into permanent residential care for people living with dementia and their informal carers. Literature that explores concepts of Person Centered Care Principles (PCCP), choice and inclusion will be examined to identify gaps in literature.

The researcher will examine assessment documentation from a variety of local authorities and using semi-structured interviews the researcher will interview staff, who are responsible for completing assessments and staff who are responsible for the decision at panel.

An audit tool to gather data will be developed using the VIP's framework. The VIP's Model has been used successfully as a benchmarking tool to test the 'person centeredness' of various establishments and the care delivered to people with dementia (Brooker and Latham, 2016). The model sets out four major elements;

- 1. A value base that asserts the absolute value of all human lives regardless of age or cognitive ability*
- 2. An individualised approach, recognising uniqueness.*
- 3. Understanding the world from the perspective of the person identified as needing support.*
- 4. Providing a social environment that supports psychological needs.*

(Brooker and Latham, 2016)

The model then sets out twenty-five indicators linked to each of the four elements above. These indicators can be used as benchmarks for current practice in care delivery. They will form the basis of an audit tool designed to analyse and categorise data collected.

**The question for this literature review is:**

What are the themes within existing literature that demonstrate the application of Person Centered-Care Principles within the assessment and transition process for those living with dementia who move into permanent residential care?

**What the contribution to knowledge will be:**

- To develop an understanding of how person centered care (PCC) is evidenced in the assessment for admission to care.
- To understand how elements of person centered care are evidenced and incorporated in the final panel decision regarding funding for care.
- To support the development of recommendations regarding the design of assessment documentation.
- To support the development of recommendations focusing on the development of training for staff completing assessments and decision making regarding care.

**How you plan to disseminate the PhD:**

The researcher will write a paper on the outcome of the literature review. The author will also write a paper on the historical perspective surrounding the theoretical concepts underpinning Person Centered Care.

The findings of this research will support the development of best practice guidelines around the assessment and decision making process for admission to permanent residential care. These findings will be disseminated through the presentation of symposiums and workshops at local, regional and national conferences. The findings will also be disseminated through delivering presentations at national networks such as the Higher Education Dementia Network.