

Example Research Proposal

Project Title:

Caring for Individuals with Dementia: A qualitative exploration of the importance of person centred care and how well it's understood.

Lay summary of the project (*intended purpose, design, and outcomes, suitable for a non-academic audience*) (200 words max)

The purpose of this study is to explore how people who care for individuals with Dementia view person-centred care (looking at the individual rather than the illness they have, and treating everyone differently in a way that suits them). It will explore whether carers think it is important to care in a person-centred way, if they feel that they currently do it and if not why. This will be achieved in the study by interviews being carried out face to face with carers. They will be asked questions around this area and their answers will be looked at and analysed looking for similarities and differences within their answers. The study is also looking to see whether there is room for a new scale to be created which will measure people's views on person-centred care. The questions to this scale will be created using a document about person-centred care which was published by the British Psychological Society (2016). This study is being done due to it been seen that individuals with Dementia needing to be cared for in a different way so that they feel valued and important and can remain themselves for as long as they can in their life.

Background literature review? *Why is the project necessary, what psychological theory is the intervention based upon and what empirical evidence has informed this proposal. (500 words max)*

The British Psychological Society (2016) released an article called '*Psychological Dimensions of Dementia: putting the person at the centre of care*'. This article demonstrated the need and importance of Individuals looking after or supporting individuals with Dementia to focus upon the Individual themselves more rather than the labelling of the illness, by supporting the individual in continuing to make decisions about their future and withholding their identity. It is an in-depth document with knowledge in it that past and present research in person-centred care seems to be missing.

Much research has explored person centred care for Dementia patients in both qualitative and quantitative research (Gibbard & Hanley, 2008; Chenoweth et al., 2009; Clissett, Porock, Harwood & Gladman, 2013) in various care settings such as the community, hospitals and care homes (Downes & Lord, 2017; Smythe, Bentham, Jenkins & Oyebode, 2013; Surr, Smith, Crossland & Robins, 2015) though the results of all research indicates a need for more person-centred care, knowledge, guidance and training in the area (Clissett, Porock, Harwood & Gladman, 2013; Edvardsson, Sandman & Borell, 2014; Edvardsson, Watt & Pierce, 2016; Kim & Park, 2017).

In a large cluster, randomised control trial considering person centred care, dementia care mapping and usual care found that person centred care was the best method for caring (Chenoweth et al., 2009). Clissett et al. (2013) also identified the ideal way for carers to work is in a person-centred manner and that more policies are needed stating the necessity for person centred care through organisations so Individuals feel more valued. However, whilst some research shows that some carers acknowledge person-centred care it also shows that some

carers believe they cannot carry out care in this way due to aspects of their job (Clissett et al., 2013). Research has further indicated that no one individual or organisation has a consistent definition of the true meaning of person-centred care for individuals with Dementia (Nguyen, Jansen, Hughes, Rasmussen & Weckmann, 2014; Smith et al., 2014).

Through research various measures have been used to obtain data upon individual's views on person centred care such as Approaches to Dementia questionnaire (ADQ; Lintern, Woods & Phair, 2000), the Care efficacy scale (Coates, 1997) and Person-centred climate questionnaire (Edvardsson et al., 2009). However, none of these scales are solely based upon person-centred care and individual's perceptions of it. Whilst none of them portray any knowledge of person-centred care like that obtained from the BPS (2016) document and some could potentially be outdated scales.

With this literature in mind and the BPS (2016) document on person-centred care for individuals with dementia, this study looks to capture carers perceptions of what person-centred care is, how important it is and the barriers to carrying it out and whether the results correspond with the BPS (2016) document. It will also explore whether the literature around the area requires a newer more in-depth scale measurement of people's perceptions of person-centred care using the BPS (2016) as the basis for it alongside past scales in the research area.

Proposed methodology: *Please describe your study design under the following headings: (1,000 words max)*

- *The intervention*
- *Target population and participant recruitment strategy*
- *Data collection and evaluation method*
- *Primary and secondary outcome measures*
- *Planned analyses*

The proposed study will be a mixed method design with two research phases. Phase I will be the qualitative part of the study and phase II will be the quantitative part. A mixed method design is being used as both design methods have been seen to work well throughout previous research within the area (Downes & Lord, 2017; Edvardsson et al., 2014; Kim & Park, 2017; Rokstad, Vathe, Engedal & Selbaek, 2015; Smythe et al., 2013).

Phase I of the study will be face to face interviews. Before interviews participants will be given an information sheet about the study and a consent form to fill out. This will inform participants about the study context, that their participation is voluntary and they have a right to withdraw at any time. Several demographics of participants will also be obtained at this point. These will be age, gender, education, role and how long the individual has worked in care. These demographics will be obtained due to their prevalence in past research (Edvardsson et al., 2014; Edvardsson et al., 2016; Kim & Park, 2017; Surr et al., 2015). Participants will also be informed at this point that interviews will be recorded. Interviews will be structured and should last no longer than 30 minutes per one. Participants will be asked a set of simple structured questions around the area of person-centred care. Interviews will also be set out to explore and capture each participant's perception of person-centred care, how much knowledge they have on it, how important they think it is, whether they feel they carry it out and if not why.

Following interviews phase II will occur. This part of the study will be quantitative and will look at the potential of developing a small scale to be created on the perceptions of Person Centred care. This questionnaire will be solely based around perceptions and questions will fixate on some of the attributes and qualities of what person-centred care is. It will be based upon the

BPS (2016) document using the explanations and necessities it discusses to create the questions. Previous scales in the area will also be looked at in terms of their qualities to ensure the scale will be of a high standard with the potential to be worked upon in the future.

Participants for the study will be recruited through Dementia caring organisations, this will be done through the universities contacts but also through communication within the area. Organisations will be contacted so that participants can be recruited. Participants will be carers aged 18 years plus who care for or support Dementia patients in Wales. The aim is to recruit around 20-30 participants to interview for the study. This participant group has been seen to be a good sample of participants for qualitative data collection (Rokstad et al., 2015).

Data collection will include the collation of consent forms and demographic forms. Alongside, the recordings of all interviews which will be used for analysis. By Interviews being recorded it would be hoped that a thorough analysis can take place so that no data collated from participants is lost.

Primary outcomes of the study expected will be that perceptions of person-centred care vary considerably between participants and that there is still a considerable gap in knowledge of what person-centred care is and how important it is when looked at regarding the BPS (2016) document. Secondary outcomes expected are that the study will provide evidence for there to be a potential pathway for a new scale to be developed on perceptions of person-centred care using the BPS (2016) document as its basis for development.

Analysis will start with the phase I of the interviews. Interviews will be transcribed individually and then analysed using thematic analysis. Analysis of the interviews will be carried out in correspondence to the BPS (2016) document and results will be written up in a way so that it can be seen whether person-centred care is being known to carers in the way the document portrays it. This will allow room for a response to the document to be included within the results regarding whether the knowledge of person-centred care and whether the importance of it is known to carers of Dementia patients. The analysis for phase II will consist of the small-scale measurement being inputted into SPSS so that reliabilities can be run. This will allow for it to be seen whether there is a potential for a new scale measurement.

Main Ethical considerations (500 words max)

Throughout the whole of this study the British Psychological Society's research ethics will be followed (BPS Code of Human Research, 2014; British Psychological Society with Human Participants, 2014). The study will be submitted to the Universities research ethics committee before it can start, as it will have to be approved before the study can be run. Organisations will have been contacted so that participants can be recruited. This will then lead participants in to the start of the study following the BPS ethical protocols such as providing the individuals with an information sheet and consent form so informed consent can be obtained from each participant. This will provide information to participants stating that their partaking in the study is entirely voluntary and if they wish to they can withdraw from the study at any point. Participants confidentiality will be upheld throughout the study, ID numbers and pseudonyms will be used instead of participants' names so that their anonymity is kept.

There are no physical requirements of participants within the study indicating no risk of any physical harm to participants. Financial disclosure is not seen as a risk to participants within the

study due to there being no financial incentives and no questions around this area to participants. Due to the nature of the study it is unlikely that any psychological or emotional distress will occur to participants. Though, in the unlikely event this occurs participants will know they can withdraw at any time during the study if they become uncomfortable and the academic supervisor's email will be provided for participants if they have any queries or concerns. Risks to the researcher are unlikely due to all BPS ethical guidelines being followed and good research practice being upheld. However, though unlikely if risk occurred the researcher would report straight to their academic supervisor for support.

At the end of all Interviews a debrief will be given to participants. A debrief form will be provided explaining the full aims of the study. Also, a verbal debrief will be given at the end of the interview by the researcher explaining the purpose of the study, its main aims and objectives and this will allow time for the researcher to answer any questions about the study. This also provides an opportunity for the participant to ask for their data to not be used within the study if they do not feel happy with the study, though this is seen to be unlikely.

The storage of all data will be in line with the Data Protection Act (1998). As well as the Universities data protection policies and procedures being followed. These can be found at <http://uwtsd.ac.uk/library/research-data-management/>. This will ensure that confidentiality and anonymity is upheld during the study and stored in a secure manner ensuring only the researcher has access to it. The storing of consent forms and transcribing will also be kept separately to ensure that names of participants cannot be matched to their ID number or pseudonym.

What are the expected outputs from this project? (200 words max)

The expected outcomes of this study are that there will be evidence to suggest that there is a need for more knowledge and training provided to carers around person-centred care for Dementia patients. It is expected that the BPS (2016) document needs to be studied more by organisations and used as a policy within their work. As the results to this study could potentially demonstrate that person-centred care may only be being carried out to an extent and not the necessary level that is required. Outcomes of this study could initiate more research into the area and the development of new scale measures to obtain data on people's perceptions of person-centred care whilst providing reason for there to be more initiative to create more policies and procedures that need to be followed in care jobs specifically for the care of Dementia patients in a person-centred manner. This study's outcomes could potentially add to Dementia patient's lives and could be successful for improvement in care at both an independent and organisational level.

References

- British Psychological Society (2016). Psychological dimensions of Dementia: putting the person at the centre of care. *British Psychological Society Dementia Advisory Group*, 1 – 25
- Clissett, P., Porock, D., Harwood, R. H., & Gladman, J. R. F. (2013). The challenges of achieving person centred care in acute hospitals: a qualitative study of people with Dementia and their families. *International journal of nursing studies*, 50, 1495 – 1503, doi: 10.1016/j.ijnurstu.2013.03.001
- Downs, M., Lord, K. (2017). Person-centred Dementia care in the community: a perspective from the United Kingdom. *Journal of Gerontology Nursing*, 30, 1 – 7, doi: 10.3928/00989134-20170515-01
- Edvardsson, D., Sandman, P. O., & Borell, L. (2014). Implementing national guidelines for person-centred care of people with dementia in residential aged care: effects on perceived person-centeredness, staff strain, and stress of conscience. *International Psychogeriatric*, 1 – 9, doi:10.1017/S1041610214000258
- Edvardsson, D., Watt, E., & Pearce, F. (2016). Patient experiences of caring and patient centeredness are associated with perceived nursing care quality. *Journal of Advanced Nursing* 73(1), 217–227. doi: 10.1111/jan.13105
- Kim, S. K., & Park, M. (2017). Effectiveness of person centred care on people with Dementia: a systematic review and meta-analysis. *Clinical Interventions in Aging*, 12, 381 – 397, doi: 10.2147/CIA.S117637
- Nguyen, C. M., Jansen, B. D. W., Hughes, C. M., Rasmussen, W., Weckmann, M. T. (2014). A Qualitative Exploration of Perceived Key Knowledge and Skills in End-of-Life Care in Dementia Patients among Medical, Nursing, and Pharmacy Students. *Journal of Palliative Medicine*, 17, 1 – 6, doi: 10.1089/jpm.2014.0029
- Rokstad, A. M. M., Vatne, S., Engedal, K., & Selbaek, G. (2015). The role of leadership in the implementation of person-centred care using Dementia Care Mapping: a study in three nursing homes. *Journal of Nursing Management* 23, 15–26, doi: 10.1111/jonm.12072
- Smythe, A., Benthams, P., Jenkins, C., & Oyebode, J. R. (2013). development of skills for the provision of person centred care for people with the experiences of staff in a specialist mental health service in relation to Dementia. *Dementia*, 1 – 15, doi: 10.1177/14713012133494517
- Surr, C. A., Smith, S. J., Crossland, J., & Robins, J. (2016) Impact of a person-centred dementia care training programme on hospital staff attitudes, role efficacy and perceptions of caring for people with dementia: A repeated measures study. *International Journal of Nursing Studies*, 53, 144 – 151, doi: 10.1016/j.ijnurstu.2015.09.009

