Section 3: Critical Appraisal

Reflections on conducting research with partners of people living with dementia

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Abstract

As the number of people living with dementia continues to rise there is an increased expectation that family members will provide care within the home. As a result, the current empirical paper explored the experiences of individuals who provide care to their partner living with dementia and identified three themes. This critical appraisal begins with an overview of the three identified themes and the implications of the results. Furthermore, the implications of conducting research with older adults and specifically partners of people living with dementia will be discussed. Moreover, this appraisal will reflect on the strengths and limitations of the research process, in particular the procedure of ethical approval. Finally, I will reflect on the impact of completing the current study on my clinical practice.

Overview of Results

The current study utilised an Interpretative Phenomenological Analysis (IPA) approach to explore the experience of self-conscious emotions in partners of people living with dementia. Specifically, eight participants engaged in individual semi-structured interviews. As a result, three themes were identified; 'guilt as a consequence of marriage beliefs and motivator of caring behaviour', 'discussing dementia elevates embarrassment but decreases guilt' and 'difficulty of feeling proud within the traditional boundaries of marriage'. The results suggested that implicit social rules and interactions can impact upon partners' experiences of self-conscious emotions and subsequent behaviours. Moreover, the experience of self-conscious emotions is closely related to an individual's self-identity and roles. Specifically, partners are more likely to experience negative self-conscious emotions (e.g., guilt) when they feel they are not fulfilling the expectations associated with a particular role or do not have the opportunity to develop a more adaptive role when their situation changes. Moreover, partners find the experience of guilt more painful than other negative self-conscious emotions (e.g. embarrassment) and as a result will engage in behaviours that aim to avoid or reduce feelings of guilt (e.g. increased caregiving). Consequently, understanding the meaning which partners attach to caregiving and marital roles is crucial in the experience of self-conscious emotions and being a care provider.

Furthermore, this research highlighted the importance of conducting research with individuals who provide care to their partners living with dementia. With increased numbers of people living longer with dementia, more partners are finding themselves providing a caregiver role (World Health Organization, 2016). Moreover, this often involves partners who are themselves elderly and/or with their own health conditions providing specialised care and support. While it is important that researchers continue to develop their understanding of

the experiences of partners to enable them to provide care within the home for as long as possible, there also needs to be an understanding on the support that is available. Consequently, it is important that research is not exclusively aimed at a theoretical level but also has practical and clinical implications.

Reflections on conducting research with partners of people living with dementia

Conducting research with partners of people living with dementia can present a number of challenges. Specifically, ensuring that partners are able to have quiet space alone to participate in an interview can be difficult. In particular, this can be difficult due to practical reasons (i.e. their partner is unsafe to be left alone or cannot be supported by someone else) or due to feeling that they are betraying or disrespecting their partner by talking about them when they are not present. Moreover, individuals may view their home as a safe space for both themselves and their partner which they feel would be violated by a researcher discussing personal information within their home (Locher, Bronstein, Robinson, Williams & Ritchie, 2006). As a result, within the current study I offered several interview locations as an attempt to find a comfortable location for each participant. Additionally, I attempted to meet participants at a time convenient for them and their partners. For example, I conducted one interview in clinic while a participant was waiting for her husband to finish a therapeutic group. This enabled this particular participant to contribute to the study knowing her husband was safe and without disrupting her routine. Therefore, careful consideration of practical barriers that may prevent participation are important to ensure that research is accessible for all of the target population.

Furthermore, conducting research with older people who are unable or struggle to leave their homes can present further ethical dilemmas. For example, some older adults can be socially isolated and the opportunity to interact with another person, even for research

purposes, can influence their decision to participate (Locher, et al., 2006). As a result, this raises questions about informed consent and what this means to an older adult population. Furthermore, interviewing people within their own home may expose researchers to issues occurring within the home. For example, researchers may witness incidents of neglect or abuse which they feel they need to report. Moreover, researchers have an ethical responsibility to participants but cannot provide support within a therapeutic role . However, it can be difficult to clearly state when researchers intervene in 'sub-threshold' situations of concern. Consequently, the role of a researcher needs to be flexible and have good supervision in order to respond to risks should they occur within a participant's home.

Additionally, not having a clearly defined researcher role can have implications for how participants view the purpose of the research. Specifically, some older adults may find it a novel experience to be asked their opinion or experiences of health care. Moreover, individuals may state that they will participate in the research to help other people as they believe there is little they can offer other than this (Greenwood, 2009). Specifically, this was the main reason stated for participation within the current study. Furthermore, if the researcher occupies another healthcare role (e.g. psychologist) individuals may feel that their decision about participation may have implications for the health care they receive. In particular, older adults may believe that by participating in research that has been suggested by a healthcare professional will appear more favourably when attempting to seek future support (Steinke, 2004). Similarly, individuals may believe that the study itself is a form of treatment or care due to the professional role of the researcher (Lidz & Applebaum, 2002). Consequently, the implicit power imbalance of health care professional and service user can have implications for the research relationship prior to the start of the study.

Strengths and Challenges of the Research Process

The current study was reviewed by an NHS Research Ethics Committee (REC) and the Health Research Authority (HRA). During the process of obtaining REC approval the procedures for obtaining ethical approval for NHS studies was updated to include further HRA approval. Unfortunately, despite several prompts this resulted in a delay of several months while waiting for this additional approval. Moreover, the additional information required for HRA approval included having a more in depth knowledge about the practicalities of the study (e.g. resource and cost implications). While this process was time consuming and complex, it ensured that the content of the study and any materials used were appropriate for the target population.

Furthermore, prior to submitting the study information to the REC and HRA panels I sought feedback from two members of a local service user group. This feedback contributed to the redevelopment of some of the materials used within the study and ensured that difficult issues were being discussed in a sensitive way. For example, throughout the research process careful consideration was given to the language used particularly in relation to how participants were described. I consciously avoided the term carer as it was anticipated that participants would not necessarily identify with this label and the connotations it involves (Greenwood, 2009). Consequently, having multiple forums to reflect on how participants may experience the research process was important in ensuring that I had considered my impact upon the research process.

Additionally, various methods of participant recruitment were explored during the design of the study. Specifically, I wanted to utilise an approach which maximised the number of people who could participate in the study without feeling under pressure to do so. As a result, utilising existing relationships between service users and their partners via

memory service nurses was considered to be the most effective recruitment procedure.

Although I was keen to recruit a variety of individuals (e.g., varying length of time since

partner's diagnosis) to include a diverse range of experiences, recruiting participants through

a structured service, such as memory service, does limit the population which can be

accessed. In particular, individuals who had contact with the service during the recruitment

period were more likely to be seeking support within the early stages of dementia or were

experiencing difficulties. Moreover, individuals who were experiencing difficulties at that

time may have been reluctant to participate in a research project due to other priorities and

time constraints. Consequently, attempting to recruit such a specific group of participants

resulted in difficulties in recruiting the minimum number of participants for the study.

As a result, the inclusion criteria was reviewed to widen the target population without

compromising the integrity of the study. The initial inclusion criteria only included

individuals whose partner was living with Alzheimer's disease or vascular dementia.

Moreover, it was anticipated that as Alzheimer's disease and vascular dementia are the two

most common forms of dementia other people would have a better understanding and

therefore there would be more service provision and social support. Additionally, there is

often more support available for individuals living with these specific diagnoses, including

peer support groups. However, after further consideration it was anticipated that including

individuals whose partner had a diagnosis of other types of dementia would not be

detrimental to the homogeneity of the sample. Specifically, the focus of the study was the

experiences of partners rather than the individuals living with dementia and therefore it was

anticipated that differences in presentation would not impact too greatly upon the results. As

a result, an amendment was submitted to both REC and HRA panels to include individuals

whose partner was experiencing any type of dementia. Interestingly, this amendment only

resulted in the recruitment of one additional participant, whose partner was living with Lewy

bodies dementia. It is anticipated that this was due to the majority of individuals involved with memory services having a diagnosis of either Alzheimer's disease or vascular dementia. Consequently, this study highlights the difficulties in accessing a diverse population of partners who provide care to individuals living with dementia and therefore future research should consider how this can be improved.

Impact of the Research upon my Clinical Practice

The idea and enthusiasm for this study was the result of working with family members of people living with dementia within a carers support group. Specifically, the group was designed to provide psycho-education about dementia in addition to self-care techniques and strategies. Despite many carers reporting that they found the psycho-education sessions helpful they struggled to engage and attend sessions that focused upon their needs and experiences. As a result, I was interested in how partners of people living with dementia feel about themselves and what can be done to promote more positive emotional experiences.

Furthermore, as I continue to work with people living with dementia and their families, the current study has influenced my clinical practice in a number of ways. Specifically, the current study highlighted the importance of partners feeling connected to others to reduce experiences of guilt. Moreover, connecting to other people was more than feeling that other people understood their current situation but they could experience true empathy and relate to their experiences. This was often acknowledged through an exchange of personal experiences with health care professionals or other family members. As a result, I have reflected upon my own position on self-disclosure and how this may impact upon the therapeutic relationship. Additionally, I have also considered how professionals can support meaningful relationships to develop between carers. For example, facilitating peer support groups for partners who have key characteristics in common (e.g., length of time since

partner's diagnosis or gender) would maximise the opportunity for partners to share similar experiences. Furthermore, ensuring that these relationships are nurtured and protected over time may involve providing practical support, such as facilitating groups for people living with dementia at the same time and locations that carers groups are being held. However, it is acknowledged that this would initially be resource intensive for services and there may be limitations as to what could be provided following an individual's admission to long term care. Consequently, clinical psychologists have an important role in contributing to service development plans in order to highlight the effectiveness of working at a systemic level within dementia care.

I have considered how I will disseminate the understanding developed from the current study to other health care professionals. Specifically, it is important to share knowledge about factors that may be contributing to specific caregiving behaviours. For example, understanding what being a partner or care provider means to an individual may help identify why some partners are reluctant to accept support or other interventions. Moreover, utilising a formulation model, such as the CBT model of depression for older adults (Laidlaw, Thompson & Gallagher-Thompson, 2004), would acknowledge the impact of individual and cohort beliefs on an individual's behaviour. However, there is also a need to ensure that emotional experiences are incorporated and highlighted within structured formulation models. Therefore, incorporating emotional experiences in addition to the meaning of roles and identity into formulations would be an effective way of improving the understanding of other health care professionals.

Furthermore, within my own practice I am frequently conscious of how this information is shared with partners themselves. Specifically, discussing experiences of self-conscious emotions which people believe are socially unacceptable requires some

consideration.   As a result, where possible I continue to develop the formulation with partners in a way that was meaningful to them (e.g. including their choice of words) and with opportunity for interventions and support.   Additionally, it is important to consider gaining consent from partners to share this information with other teams when it is appropriate.   For example, the recent literature review suggested that partners found it difficult to relate to care home staff when they did not have an understanding of both them and their partner's background.   Consequently, it is imperative that dementia care is understood and delivered at a systemic level rather than directed at the individual to ensure that people living with dementia are supported at home as long as possible.

Furthermore, when working with partners of people living with dementia consideration needs to be given to the terminology used when describing their role. Specifically, there is an active debate about the use and implications of the term 'carer' (Molyneaux, Butchard, Simpson & Murray, 2011).   In a qualitative study conducted with family members who provided care, participants did not identity with the label 'carer' despite acknowledging that they were providing care to their relative.   Instead, individuals perceived the care they provided as part of their relational position rather than a distinct carer role (O'Connor, 2007).   Similarly, participants within the current study described providing care for their partner as a marital obligation or duty and therefore did not identify themselves as carers.   However, in O'Connor's (2007) study it was noted that family members described themselves as carers when attempting to access services and engage in dialogues with healthcare professionals.   Therefore, this would suggest that family members of service users are adapting their language and understanding of their role to be consistent with healthcare professionals.   Consequently, this demonstrates the power imbalance that often occurs between family members who provide care and healthcare services.

Despite increasing research regarding the effects of caregiving, a limited understanding remains into the experience of caregiving within specific populations. In particular, few studies compare the impact of cultural beliefs on caregiving behaviour and experiences. For example, within some eastern cultures there is an expectation that women provide care to their elderly in-laws (Youn, Knight, Jeong, & Benton, 1999). However, given the findings of the current study it would be anticipated that these expectations would have consequences for how the women feel about themselves but currently this is not fully understood. Moreover, we would expect there to be differences in the experience of caregiving between people living in individualistic and collectivist cultures. Furthermore, due to changing demographics of the world's population there are more people providing care to multiple individuals (e.g. elderly parents and children). As a result, understanding how the care providing role is constructed and experienced across different cultures and how this changes over time is crucial in supporting both people living with dementia and their carers to live well.

Conclusion

The current study explored how people who provided care to their partner living with dementia felt about themselves. Specifically, the study recruited and interviewed eight partners through a local memory service. Throughout this process it was acknowledged that it was difficult to recruit participants from this specific population due to practical and ethical issues. As a result, understanding the experiences of partners who provide care is a relatively underdeveloped area, particularly with specific subgroups and cultures. However, it is important that solutions to the barriers of accessing this population are explored so that the needs of care providers can be understood and met. Moreover, it is crucial that this information is disseminated at a service level, for example shared with team members

through individual formulations and case consultations. Additionally, this study has had

implications for my own clinical practice, including my perceptions of the importance of

appropriate self-disclosure in the therapeutic relationship with care providers.

References

Greenwood, N. (2009). Reflections of a researcher interviewing older people. *Nursing Older People, 21*(7), 30-32. doi:10.7748/nop2009.09.21.7.30.c7279

Laidlaw, K., Thompson, L. W., & Gallagher-Thompson, D. (2004). Comprehensive conceptualization of cognitive behaviour therapy for late life depression. *Behavioural and Cognitive Psychotherapy, 32(*04), 389-399. doi:10.1017/S1352465804001584

Lidz, C. W., & Appelbaum, P. S. (2002). The therapeutic misconception: problems and solutions. *Medical Care, 40*(9). doi:10.1097/01.MLR.0000023956.25813.18

Locher, J. L., Bronstein, J., Robinson, C. O., Williams, C., & Ritchie, C. S. (2006). Ethical issues involving research conducted with homebound older adults. *The Gerontologist, 46*(2), 160-164. doi:10.1093/geront/46.2.160

Molyneaux, V., Butchard, S., Simpson, J., & Murray, C. (2011). Reconsidering the term 'carer': a critique of the universal adoption of the term 'carer'. *Ageing and Society, 31*(3), 422-437. doi:doi.org/10.1017/S0144686X10001066

O'Connor, D. L. (2007). Self-identifying as a caregiver: exploring the positioning process. *Journal of Aging Studies, 21*(2), 165-174. doi:10.1016/j.jaging.2006.06.002

Steinke, E. E. (2004). Research ethics, informed consent, and participant recruitment. *Clinical Nurse Specialist, 18*(2), 88-97. doi:10.1097/00002800-200403000-00014

World Health Organization (2016). Dementia: fact sheet. Retrieved from http://www.who.int/mediacentre/factsheets/fs362/en/

Youn, G., Knight, B. G., Jeong, H. S., & Benton, D. (1999). Differences in familism values

and caregiving outcomes among Korean, Korean American, and White American

dementia caregivers. *Psychology and Aging, 14*(3), 355. doi:10.1037/0882-

7974.14.3.355