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How do daughters experience having a mother with dementia?

ABSTRACT

Background/Objectives:

There is a paucity of research on the experience of daughters of mothers with dementia, who do not live together. This research explores how daughters experience having a mother with dementia.

Method: Seven semi-structured interviews with daughters of mothers with dementia, were conducted. Interview accounts were analysed using thematic analysis.

Results: The main themes of Bewilderment and Fear, and Transformed Relationships were identified. The analysis indicated that the experiences described were, at times, distressing for the daughters and there was a perceived lack of professional help to support both mothers and daughters through the changes. However, the analysis also indicated that some daughters experienced transformative ways to make thoughtful new connections and aspects of the relationship with their mothers were described as having improved.

Conclusions: It is proposed that it could be helpful if professional services recognised that having a mother with dementia can be a challenging experience, even if mothers and daughters do not live together. It is also proposed that services need to continue to be improved for both mothers and daughters.

Key words:

Dementia, Mother-Daughter Relationships, Fear, Transformed relationships, New Connections.

Background and Literature

The ICD-10 classification of mental and behavioural disorders describes dementia as a syndrome due to disease of the brain, usually of a chronic or progressive nature (The World Health Organisation, 2015). Alzheimer's Research UK (2016) estimates that there are 850,000 people in the UK living with dementia. There are a larger amount of women with dementia as sixty two per cent of this number are women and thirty eight per cent are men (Alzheimer's Research UK, 2016).

Studies of carers of those with dementia have largely investigated the concept of burden, which has been the subject of research for some decades (van der Lee, Bakker, Duivenvoorden & Droes, 2014). Examples of other difficulties identified are anxiety and depression (Cooper, Katona, Orrell, & Livingston, 2008), and loss (Ingebretsen & Solem, 1998). There have been a few examples of positive aspects of the experience for family members within the literature; these include closer relationships (Street and Mercer, 2014), personal growth (Ott et al, 2007) and a contribution to the carers' spiritual life (Baldwin & Capstick, 2007).

Rationale for this project

There is a lack of dementia research by clinical professionals (Alzheimer's Society Research Report, 2015). It therefore seemed important to try to make a small contribution to the research about therapeutic work in this neglected area, which may have implications for practice. Daughters rather than other family members have been interviewed as, after spouses, it is usually adult daughters who become primary caregivers for older adults (Brody, 2004). This study focused on mothers

with dementia rather than fathers as there are more women than men with dementia¹ (Alzheimer's Research UK, 2016). Daughters not living with their mothers have been chosen as most research in this area has concentrated on primary carers and "little research has focused on wider family members" (Street and Mercer, 2014, p.4).

Methodology

A qualitative study using thematic analysis from a critical realist epistemological position was undertaken. Willig (2008) commented that qualitative researchers are largely concerned with meaning and they are interested in how people make sense of the world and how they experience what happens around them. Braun and Clarke (2006) comment that thematic analysis can be a 'contextualist'² method which lies between essentialism³ and constructivism⁴ and can be characterised by theories such as critical realism. This approach acknowledges the way individuals make sense of their experience and the way the broader social context impacts on this (Braun and Clarke, 2006). It can also be useful for informing policy development (Braun and Clarke, 2006). This emphasis on individual meaning, acknowledgement of the broader social context, and the possibility of informing policy seemed appropriate for this topic.

¹ It is noted that although this study focuses on the experiences of daughters, it is not to negate the experience of other family members.

² A doctrine which emphasizes the importance of the context of enquiry in a particular question (Oxford Dictionary, 2015).

³ A belief that things have a set of characteristics which make them what they are, and that the task of science and philosophy is their discovery and expression (Oxford Dictionary, 2015).

⁴ A philosophical (specifically epistemological) stance in phenomenological sociology in which social realities are seen as the product of socio-historically situated practices rather than objective facts (Oxford Reference, 2015).

Table of information regarding mothers and participants

Name of daughter	Age of daughter at time of interview	Age of mother/ stepmother at the time of the interview	Type of dementia
Isobel	50	78	Dementia with Lewy Bodies
Natalie	55	84	Alzheimer's
Carol	66	90	Alzheimer's
Maggie	62	90	Dementia
Susan	54	84	Vascular Dementia
Martha	64	91	Vascular Dementia
Deborah	53	88	Dementia

Seven daughters who were not living with their mothers were interviewed, their ages ranged from 50 to 66. Five participants were recruited through the snowballing method. These daughters were colleagues or acquaintances of friends or colleagues of the researcher; who had not had any contact with them prior to the interviews. The seventh participant was recruited at a presentation after she had talked of having a mother with dementia. The mothers' ages were from 78 to 90, they had a range of dementia diagnoses and time since they had been diagnosed. Interviews were audio recorded and conducted using a schedule of 20 guiding questions, which included "open" questions. The research questions were broad to allow topics or themes to emerge during the interviews and analysis (Smith, 2004). The following are two examples from the interview schedule – "Can you tell me how your mother's dementia has affected your life?" and "Can you tell me how your mother's dementia has affected your relationship with her?" Most interviews lasted for approximately an hour. Ethical approval was granted by the Research Ethics Committee of the School of Psychology, University of East London. Participants were offered help in finding details of local counselling services if they needed them at any time after the interviews. Transcripts were read and re-read and interviews were listened to several

times. Preliminary notes were initially descriptive comments but gradually became more interpretative.

Results

Main themes and sub themes emerged during the analysis (see table below).

Table of Themes

Main themes	
Bewilderment and Fear	Transformed Relationships
Sub themes	Sub themes
Resisting Knowing	Contrasts
Confusing Behaviour	Feelings Regarding the Transformed Relationship
Uncertainty	Lost Connections
Professional Help; Absent and Disengaged	New connections

Theme of Bewilderment and Fear

Resisting Knowing

Four of the daughters talked about the different ways they resisted knowing that their mother's difficulties were symptoms of dementia. Susan and Natalie's bewilderment, fear, and resistance is evident in the following extracts. Susan noticed how her mother asked the same questions four or five times. Instead of thinking that there may be a difficulty that needed acknowledging, she says:

At first I didn't sort of pick up on it... I mean, it's at the back of your mind, but you don't want to really think... (Susan)

Natalie commented on her mother's confusion as follows:

We were all in denial. (Natalie)

Confusing Behaviour

Daughters struggled to make sense of some of their mothers' behaviour. Martha described how her mother would become "very annoyed" when her memory had failed her about where they were meeting. Martha makes sense of this by offering a thoughtful explanation that her mother's anger is a way of denying her own difficulties because she is scared:

it wasn't about having an argument about something, it was about if I've got it wrong something's the matter with me. (Martha)

Maggie's extract describes confusing behaviour as her mother repeatedly feels that the doorbell is ringing when it is not. Maggie's frustration is apparent when the bell still rang (in her mother's mind) and her mother kept calling the police as she felt threatened:

...she kept on thinking that the doorbell had gone [rung] in the night... and I said "It's unplugged" but she said "but it rang in the night" ...she kept calling the police. (Maggie)

Uncertainty

Daughters gave examples of their uncertainty around their mothers' dementia. Maggie, Natalie, and Carol anticipated a fearful future in which they would not be able to manage situations around their mothers' dementia and they expressed the extent of their anxiety in the following way, "worry terribly", "constant worry", and "dread the phone ringing".

Susan implied that the things that she had seen on television, and had read, about dementia, fed into the fear of the future and how her life would change for the worse.

You start to think there's things that you've seen on the TV or things that you've read about, so I started to think, oh God, my life's gonna change. (Susan)

Professional Help; Absent and Disengaged

Although not all professional help was absent and disengaged, daughters gave examples of times when they were deeply disappointed with the help their mothers received. In the first extract below, Carol uses the metaphor of the doctor being invisible to convey how little he was seen.

*my mother's doctor in H... was...we called him the invisible man, ...hardly believed he existed, because he showed **so** little interest in what was happening to her. (Carol)*

Martha used strong adjectives of “awful” “appalling” and “humiliating” to convey her upset about her mother’s care in hospital, which was very distressing for both her and her mother.

It was an awful ward... I just thought that's appalling, the nurses shouldn't have put her in that position, it's humiliating and they can't seem to work out what the matter is... it was awful. (Martha)

Natalie, like Martha, was also not happy with the professional staff (at her mother’s care home) and came to the painful conclusion that the staff did not like her mother and were frightened of her:

I don't think the staff at the first home understood her at all or I don't think they liked her very much, quite honestly they were frightened of her. (Natalie)

Six daughters gave examples of when their mothers were, at times, feared, ignored, disliked, humiliated, and dismissed in a way that highlights the profound lack of care for the mothers that seemed painful for the daughters to witness.

Theme of Transformed Relationships

Contrasts

Five daughters highlighted the extreme changes in their mothers, for example, from “fiery to quiet”, from “vibrant to zombie”, “from intelligent to talking rubbish” and “from

best friend to totally ruined". Some daughters described their mothers as being strangers or feeling not liked by them, which conveyed the feeling of unfamiliarity in the relationship. Susan's portrayal of her mother prior to dementia contrasts with the present mother; the following extracts convey the stark difference in her.

*she's just a **completely** different person, she was **so** fiery and chatty... she just sits there like a small part of herself you know... (Susan)*

Maggie described the enormous and painful realisation that "she is not coming back" and that she did not need her anymore; this illustrates the significant change in their relationship.

I don't need her as she is now... If she was still as she was, it would be lovely, but she isn't and I know she'll never come back. (Maggie)

Feelings About The Transformed Relationship

Three daughters said that talking about the situation was helpful and a fourth daughter found it helpful to express herself by crying. Isobel and Martha said that it was helpful to talk to others about the situation with their mothers.

Susan is also able to identify what would be helpful for her but suggests that she is not able to have this need met. She describes how people do not want to ring her up and talk about it, "they think it's upsetting to you". Susan identifies a strong need to "offload" before she is able to relax after visiting her mother but she says sadly that she has not got anyone to experience it with:

I want to sort of offload it and I suppose, talk about it... I've got nobody to, you know, experience it with me... (Susan)

Unlike the other daughters, Maggie wishes to express her distress on her own. She does this regularly and in a loud way on her journeys to and from visits to her mother, in the privacy of her car; it is both unwitnessed and unshared:

I go on my own and...I do a lot of crying and screaming in the car... and that time I'm on my own and you know I can do what I like no one can hear and it really gets it out of your system and I realised that basically my mother was dead... (Maggie).

Most daughters found talking helpful but not all daughters had the opportunity to do this. Maggie was unusual in this regard as she preferred to, and found ways to, express her feelings alone.

Lost connections

Some daughters tried to connect in old, previously established, ways which were no longer successful. For example, daughters tried to laugh with their mothers, discuss politics, and have a conversation. Carol tried to make a connection with her mother by asking if she wanted to have part of the newspaper read out to her but her mother replied as follows:

"I don't care what's going on in the outside world." She [Carol's mother] used to care a lot about it, so basically I don't think she's got any interest in anything...all gone. (Carol)

Carol portrays sadness when she talks of the things her mother used to do that she is unable to do now. She uses the words "all gone" to stress how her mother has lost interest in her hobbies and, by implication, this makes it hard for Carol to have a connection with her mother.

Maggie commented sadly on her loss as follows,

I realised that basically my mother was dead, my mother didn't exist anymore um, so I think I grieved for her then um because I couldn't really say that this isn't my mother. (Maggie)

New Connections

Some daughters described seeing positive aspects of the changes. Daughters made the following comments about their present mothers: "she [']s still can be enormous

fun”, “she had this **amazing** bit of insight”, “emotionally really accessible” and “being less inhibited than she was”. Four daughters described thinking of imaginative new ways of achieving intimacy with their mothers, such as, cuddling, singing, looking at art and photographs together, and discussing the distant past.

Deborah presented an account of her relationship with her stepmother as a private, unique, and special relationship.

I'd just get up on her bed and give her a cuddle ...that she would find that very comforting, so I think, you know...I also understood what she was going through and we could talk. (Deborah)

Other daughters described new connections with their mothers. Natalie sounded surprised by this but seemed really pleased that her mother was still able to have a two-way teasing conversation.

...she's, she's still can be enormous fun... in fact she is almost more fun now she is less inhibited than she was, in a way. (Natalie)

Martha described how she achieved intimacy with her mother as follows:

...but this kind of intimacy of the last year... a real sense of what she might have been like as a young woman...some of that shines through. So I think overall it would have been better for her not to suffer this... in some ways I have got something from it which I didn't have before. (Martha)

Discussion

As mentioned, main themes of *Bewilderment and Fear* and *Transformed Relationships* emerged during the analysis. The subthemes with the most relevance to clinical services will be discussed.

Resisting knowing

Balfour commented as follows, “In a sense, we may all share a tendency to wish to deny something felt to be so unbearable” (Balfour, 2007, p.225). This may explain, at least in part, why some daughters resisted acknowledging changes in their mothers. It may be helpful for psychologists and other health professionals to be aware of this resistance, to support daughters with what is happening to their mothers.

Confusing Behaviour

Daughters struggled to make sense of strong emotion, such as anger, in their mothers. This could be understood in psychodynamic terms. Garner’s (2004) idea that the person with dementia may project unacceptable feelings onto others seems to be a helpful one and supports Martha’s understanding of confusing behaviour, that is, her mother’s fear manifesting as annoyance. This led to her being able to stay closer to her mother emotionally. This understanding may be a very useful insight for psychologists and other health professionals to help with interactions that were sometimes experienced by the daughters as attacks on them.

Professional Help; Absent and Disengaged

Almost all the daughters found NHS professionals to be absent and disengaged for their mothers and they themselves were not offered support. A possible reason for the difficulties regarding mothers being inadequately supported might be one that Balfour (2006, p.341) proposes in that “Without containment and support, they [the staff in institutions] can find themselves acting in ways that echo the difficulties of their patients”. It may be that the staff were not supported and contained adequately and this led them to experience a fear of dementia and a lack of capacity to adequately support many of the mothers in this study. A greater understanding of

the difficulties that professionals experience when working with people with dementia and their families may also lead to improvements in the quality of care offered.

Although the focus of this research is on individual daughters, it seems likely that if psychological therapy was widely available for those with dementia, the experience may be less distressing for both mothers and daughters. In terms of therapy for people with dementia, Ng (2009, p.202) puts forward the disappointing view that, “Despite the scale of the problem, provision of psychological support to this group [people with dementia] is diminutive in comparison with other illnesses”. Kitwood (1997, p.14) offers a suggestion for the possible fear in psychologists and other health professionals:

There is no real consolation in saying ‘It won’t happen to me’ in being close to a person with dementia we may be seeing some terrifying anticipation of how we may become.

A persuasive argument for the provision of therapeutic services for people with dementia, highlighted by Ng, (2009) is that, although it affects cognitive abilities, it does not mean a loss of emotions, and therapists could concentrate on working with the person’s emotions.

Although daughters and their mothers in this study did not have access to psychological help, there have been some innovative initiatives from psychologists and other professionals. The British Psychological and Department of Clinical Psychology (2006) produced a briefing paper providing information about the role and function of Clinical Psychologists working with older people, their families, and other carers. The British Psychological and Department of Clinical Psychology also produced a useful summary of documents – Dementia Pathways (2013) outlining services that could inform dementia treatment. Positive initiatives offering

psychological therapy for people with dementia have been established and are available now in some areas for individuals with dementia and/or their families. For example, Age UK Camden⁵ (available for people in Camden) and the University College London, Specialist Cognitive Disorders Clinic, have specialist services which offer individual therapy for people with dementia. Further examples of initiatives for people with dementia include: “Living Together with Dementia⁶”, a research project offering therapy to couples where one partner has dementia, was launched in 2013, by the Tavistock Centre for Couple Relationships.

Expressing Feelings Regarding the Transformed Relationship

The daughters in this study were not offered any help to assist them in understanding their experience or given the opportunity to express their feelings. The purpose of the interviews was not a therapeutic intervention but some daughters expressed how positively the interview had impacted upon them. This was surprising as the interviews for these daughters were short (most were just over an hour). For example, Maggie stated that the interview had started her off in rebuilding her life, Natalie said it was cathartic, Susan said it was helpful to offload and Martha commented that it helped her ‘pull things together’. This supports the research of Butterfield, Borgen, & Amundson, (2009) when participants of a qualitative study indicated that their interview had led to them to gain insight into issues that they had not thought of before.

The Department of Health (2015) recognises the need for support for carers and families when they state, “our vision is to create a society by 2020 where every

⁵ “...the Counselling Service provides emotional support for older people with early stage dementia, including Alzheimer’s disease.” (Age UK, Camden). NB: This is the only borough in London that offers this support through Age UK.

⁶ Available in a limited number of Boroughs in London.

person with dementia, and their carers and families...receive high quality, compassionate care from diagnosis through to end of life care". Furthermore, Admiral Nurses offer support in some areas. They are "specialist dementia nurses who give expert practical, clinical, and emotional support to families living with dementia to help them cope" (Dementia UK, 2015). In addition, an encouraging initiative launched by the Alzheimer's Society in 2013, is 'Dementia Friends'. The society trains the wider population to learn about dementia.

Lost connections

This was identified in the study as a theme and does not seem to have been explicitly mentioned in the dementia literature, as far as is known. It may come under the umbrella term of "loss" which has been outlined in the context of spousal caregivers. For example, Ingebretsen and Solem (1998, p.151) comment that in spousal caregivers dementia may result in "losing a discussion partner". This "losing a discussion partner" also seems to be relevant to the daughters in the present study as Susan, Carol, Maggie and Natalie give examples of being no longer able to "have a laugh", "discuss politics", "sit and talk all day" or "have a proper conversation". This has some aspects in common, and supports aspects of Street and Mercer's (2014) findings in their study on wider family members of women with dementia, when they outline that previous rapport and shared experiences no longer existed as part of the relationship.

New Connections

Most studies regarding caregiving have emphasised negative outcomes (Szinovacz, 2003). Although daughters in this study also talked in terms of negative experiences, four daughters described *New Connections* with their mothers, and three daughters described improvements in aspects of their relationships, compared to the

relationships before their mothers' developed dementia. This contradicts the large number of studies that focus on only negative aspects of having a relative with dementia. It also extends the existing, but limited, amount of research in the literature which has identified some positive aspects of having a relative with dementia. As stated above, Ng (2009) commented that, although dementia affects cognitive attributes, it does not mean a loss of emotional attributes. This means, as illustrated by some daughters, that communication can have an emotional focus rather than a cognitive one. In the present study, one daughter described feeling closer to her stepmother than before her mother's dementia and another described an "intimacy that might not have happened". A third daughter describes her mother as "being in some ways more fun". These may be seen as examples of daughters connecting, in line with Ng's (2009) comments, in an emotional rather than in a cognitive way.

Conclusions and clinical implications

This research used a small number of participants and any conclusions are tentative. It seems as though it is particularly important for counselling psychologists, other therapists, and health professionals to be aware of the possible challenges of having a mother with dementia when working with clients. This could be on an individual basis with daughters, for example, giving them an opportunity to express their feelings about loss but also to help with understanding angry or confusing behaviour in their mothers. This could help daughters to move towards their mothers emotionally, rather than away from them, and subsequently assist them towards forging new and meaningful connections with their mothers. In addition, if mothers were offered psychological therapy in the early stages of dementia, this may be helpful for reducing anxiety and distress in mothers and subsequently lead to

reduced anxiety in daughters. Although the focus of this research is mothers and daughters, it is likely that a consideration of the difficulties that anyone close to someone with dementia could be experiencing may be helpful.

The research highlighted a complex fear from professionals and society at large that seemed to impact on the individual experience of the daughters. This seemed to be an example of the way in which societal context encroaches on individuals and, in this case, the experiences for the daughters. So, although the focus of this research is on individual experience, and more individual help would be appropriate, implications for clinical practice seems to be wider than this. These may include considering how the experience of having a relative with dementia is embedded within, and shaped by, the broader socio-political context. This could influence not only how services are set up and funded but how dementia is spoken about and portrayed. This fits well into the ethos of counselling psychology as it “places a commitment to understanding social context and socio-political processes at the heart of its mission” (Raflin, 2010, p.49). In addition, counselling psychologists and other therapists could contribute to reducing the fear around dementia by addressing the issues rather than neglecting them. Maciejewski (2001, p.26) makes an important point; she suggests that the challenge is to “communicate the value of psychological perspectives in dementia care”. It seems that there have been initiatives resulting in progress in this area over the last few years. There are now excellent services available to some people with dementia and their families. For services and support to continue to increase there needs to be a strong motivation and commitment to argue for services along with a willingness to work in them.

REFERENCES

Alzheimer's Research UK (2016). *Facts and Stats*.

Accessed: 15 January 2017, from:

<http://www.alzheimersresearchuk.org/about-dementia/facts-stats/10-things-you-need-to-know-about-what-dementia-research-achieves/>

Alzheimer's Society (2015). *Dementia Friends*.

Accessed: 8 January 2017, from:

<https://www.dementiafriends.org.uk/>

Alzheimer's Society Research Report (2015). *A Review of the Dementia Research Landscape and Workforce Capacity in the United Kingdom*.

Accessed: 15 January 2017, from:

<https://www.alzheimers.org.uk/researchreport2015/>

Baldwin, C., & Capstick, A. (eds.) (2007). *Tom Kitwood on Dementia: A Reader and Critical Commentary*. Berkshire: Open University Press.

Balfour, A. (2006). Thinking about the experience of dementia: the importance of the unconscious. *Journal of Social Work Practice*, 20 (3), 329-346.

Balfour, A. (2007). 'Facts, phenomenology, and psychoanalytic contributions to dementia care' in Davenhill, R. (ed.) *Looking into Looking Later Life: A Psychoanalytic Approach to Depression and Dementia In Old Age*. London: Karnac Books, 222-247.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2), 77-101.

The British Psychological Society and Division of Clinical Psychology (2006). Briefing Paper 5, *Commissioning Clinical Psychology Services for older people, their families and other carers*.

The British Psychological Society, Division of Clinical Psychology. Faculty for the Psychology of Older People (2013). *Summary of documents, Dementia Pathways*.

Brody, E. M. (2004). *Women in the middle: Their Parent-Care Years*. 2nd edn. Springer: New York.

Butterfield, L. D., Borgen, A., & Amundson, N. E., (2009) The impact of a Qualitative Research Interview on Workers' Views on their Situation. *Canadian Journal of Counselling*, 43 (2), 120-130.

Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008) Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 23, 929-936.

Dementia UK. Admiral Nursing (2015).

Accessed: 8 January 2017, from:

<https://www.dementiauk.org/how-we-help/admiral-nursing>

- Department of Health: Prime Minister's Challenge on dementia. (2016) (2015) Accessed: 2 February 2017, from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-4/pm-4
- Garner, J. (2004). 'Dementia', in Evans, S., & Garner, J. (eds.) *Talking over the Years: A Handbook of Dynamic Psychotherapy with Older Adults*. Hove/New York: Brunner-Routledge, 215-231.
- Ingebretsen, R., & Solem, P. E., (1998). 'Spouses of persons with dementia: Attachment, loss and coping'. *Norwegian Journal of Epidemiology*, 8 (2), 149-156.
- Kitwood, K. (1997). *Dementia Reconsidered: the person comes first*. Milton Keynes: Open University Press in Baldwin, C. & Capstick, A. (eds.) (2007) *Tom Kitwood on Dementia, A Reader and Critical Commentary*. Berkshire: Open University Press.
- Maciejewski, C. (2001). 'Psychological perspectives', in Cantley, C. (ed.) (2001) *A handbook of dementia care*. Buckingham: Open University Press, pp.26-43.
- Ng, A. N. (2009). 'Making sense of dementia using infant observation techniques: a psychoanalytic perspective on a neuropathological disease'. *Infant observation*, 12, 83-105.
- Ott, C., Sanders. S. & Kelber. M. S. (2007). 'Grief and Personal Growth Experience of Spouses and Adult-Child Caregivers of Individuals With Alzheimer's Disease and Related Dementias'. *The Gerontologist*, 47 (6), pp. 798-809.
- Rafalin, D. (2010). 'Counselling Psychology and Research: Revisiting the Relationship in the Light of Our "Mission" in M. Milton. (ed.) *Therapy and Beyond Counselling Psychology Contributions to Therapeutic and Social Issues*. West Sussex: Wiley-Blackwell, pp.41-55.
- Smith, J.A. (2004) 'Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology', *Qualitative Research in Psychology*, 1, pp. 39-54.
- Street, R. & Mercer, J (2014). 'Coping with relationship change: A phenomenological study of relatives of people with dementia', *Health Psychology Update*, 23 (1), 3-10.
- Szinovacz, M. E., (2003). 'Caring for a demented relative at home: Effects on parent-adolescent relationships and family dynamics', *Journal of aging studies*, 17(4), pp. 445-472.
- van der Lee, J., Bakker, T., Duivenvoorden, H. J., & Droes, R. M. (2014). 'Multivariate models of subjective caregiver burden in dementia: A systematic review', Article in press. *Ageing Research Reviews*, 15, 76-93.
- Willig, C. (2008). *Introducing Qualitative Research in Psychology. Adventures in Theory and Method* (2nd edn.) Berkshire: Open University Press.

World Health Organization (2015). *The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines*. Geneva.
Accessed: 6 January 2017, from:
Available at: <http://apps.who.int/classifications/icd10/browse/2015/en#/F00>