

'Inappropriate sexual behaviour in dementia: The lived experience of caregivers'

Thesis submitted to the University of Leicester

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For the partial fulfilment of degree of

Doctorate in Clinical Psychology

By

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Declaration

I confirm that this thesis is an original piece of work. It has been submitted in partial fulfilment of the degree of Doctorate in Clinical Psychology. It has not been submitted to another institution or for any other degree.

'Inappropriate sexual behaviour in dementia: The lived experience of caregivers'

Thesis abstract

Part 1: Literature review

Aim: To review the literature and examine factors which have been identified to contribute to the job satisfaction of formal caregivers working within dementia care.

Method: 11 papers were included in the review following a systematic search of three databases.

Results: Factors found to be associated with job satisfaction in caregivers include Person Centred Care, setting type, caregiver distress, support and exposure to aggression. Several methodological limitations of the reviewed studies were noted; namely a lack of consensus on the definition of job satisfaction and a wide variety of measures utilised.

Conclusion: Due to the ambiguity of what constitutes job satisfaction precision regarding predictive factors was difficult; this is also reflected in wider healthcare literature. Future research with a qualitative design may elicit what job satisfaction means to caregivers working within dementia care.

Part 2: Research report

Aim: This study set out to explore the experience of informal caregiver's living and caring for someone with dementia who presents with Inappropriate Sexual Behaviour (ISB).

Method: Interpretative Phenomenological Analysis was used to explore the lived experience of two caregivers.

Results: Analysis across both cases revealed divergence and convergence. Three super-ordinate themes were identified: 'What the behaviour means to me', 'The change in our relationship' and 'Making sense of outsiders'. Both caregivers seemed to adopt coping strategies such as minimisation and distancing their spouse from ISB by attributing the behaviour to dementia.

Conclusion: This study provided a unique glimpse into the lives of spousal caregivers experiencing ISB and the importance of raising awareness of this behaviour. Further exploration is required to build on the current study and develop this under-researched topic.

Part 3: Critical appraisal

A reflective account of the whole research process which highlights key aspects of the journey.

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Table of contents

List of tables.....	8
List of figures	9
 Part one: Literature Review	 10
Abstract	11
1. Introduction	12
1.1 <i>Aim of the literature review</i>	15
2. Method.....	15
3. Results.....	19
3.1 <i>Methodological limitations</i>	25
4. Discussion	26
4.1 <i>Discussion of results</i>	27
4.2 <i>Future</i>	30
4.3 <i>Review limitations</i>	30
4.4 <i>Implications</i>	31
4.5 <i>Conclusion</i>	32
5. References	33
 Part two: Research report	 42
Abstract	43
1. Introduction	44
1.1 <i>Background</i>	44
1.2 <i>Aim</i>	48
2. Methodology	48
2.1 <i>Study design</i>	48
2.2 <i>Researcher context</i>	48
2.3 <i>Participants</i>	48
2.4 <i>Procedure</i>	50
2.5 <i>Analysis</i>	51
3. Results.....	53
4. Discussion	71
4.1 <i>Discussion of results</i>	72

4.2 Limitations	75
4.3 Future research	77
4.4 Clinical implications	78
4.5 Conclusion.....	79
5. References	80
 Part three: Critical Appraisal	 88
References	104
 Appendices	 106
Appendix A – Author guidelines	106
Appendix B – Process of selection for papers to be reviewed.....	108
Appendix C – Data extraction form	109
Appendix D – Quality appraisal tool	110
Appendix E – Summary of reviewed studies	111
Appendix F – Researcher context.....	117
Appendix G – Epistemological position	118
Appendix H – Letters from the ethics committee	119
Appendix I – Topic guide	127
Appendix J – Participant information sheet	128
Appendix K – ‘Opt-in’ form	130
Appendix L – Consent form	131
Appendix M – Transcript example.....	132
Appendix N – Theme development.....	133
Appendix O – Methodological rigour	135
Appendix P – Research Chronology	136

Addenda A: Interview transcripts have been submitted separately on a memory stick.

List of tables

Part one: Literature review

Table 1 Search terms.....	16
Table 2 Quality appraisal scores.....	18
Table 3 Comparison of dimensions across job satisfaction measures.....	21

Part two: Research report

Table 1 Participant demographics.....	50
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Appendices

Table 1 Quality appraisal tool.....	110
Table 2 Summary of reviewed studies.....	111
Table 3 Theme development.....	133

List of figures

Part two: Research report

Figure 1 Thematic diagram.....	54
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Appendices

Figure 1 Process of selection for papers to be reviewed.....	108
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Part one: Literature Review¹

'Predictors of job satisfaction for formal caregiving staff in dementia care'

¹ (Guidelines to authors for journal targeted for Literature Review can be found in Appendix A)

Abstract

Objectives

Job satisfaction of formal caregivers has been linked to staff turn-over and the quality of care that is provided. Staff working within dementia care face numerous difficulties and challenges which may affect their levels of satisfaction. The aim of the current study was to review the literature and examine possible predictors of job satisfaction of formal caregivers who work within dementia care.

Method

A systematic search of three databases (Psychinfo, Medline and CINAHL) revealed eighty-six pertinent articles. Following a screening of abstracts and checking suitability against inclusion and exclusion criteria eleven papers were deemed eligible for the review.

Results

A clear comparison of studies was not possible, namely due the lack of a definition of what constitutes job satisfaction and the variety of measurement scales used across the studies. Bearing this in mind, tentative results suggested that greater job satisfaction in dementia care is associated with higher levels of person centred care and colleague support, and less exposure to aggression. With regards to setting, job satisfaction was higher in care staff working in special care units for dementia or group living homes as opposed to traditional nursing homes. There were mixed findings for caregiver distress as different studies demonstrated that greater job satisfaction was found to be associated with either high or low levels of distress.

Conclusion

The difficulty of drawing a clear conclusion due to the use of different constructs and measures of job satisfaction is reflected in wider healthcare literature. Each of the studies appeared to measure different facets of the concept. Future research is suggested in terms of examining qualitative studies with a view to draw out the main themes of what job satisfaction means to caregivers.

1. Introduction

As the proportion of older adults in the population increases, the number of people worldwide living with a diagnosed dementia will also increase. By 2030 65.7 million people are predicted to be diagnosed, burgeoning to 115.4 million by 2050 (World Health Organization, 2012). The degenerative nature of dementia confers increasing disability, not only affecting cognition and personality, but also capability to live independently. Progression of dementia requires the support and care of others, most frequently informal caregivers such as family members. However, caring for a relative with dementia is often deemed the most stressful type of family caregiving (Heru *et al.* 2004; Schulz & Martire, 2004), and consequent strain and burden may prompt family members to seek formal care for their loved ones in a residential setting (Hagen, 2001).

Long term care

Although residential care may alleviate immediate pressures for family members, the challenge of dementia care may still be experienced for those delivering formal care (Brodaty *et al.* 2003; Gaugler, 2005) - any healthcare professional providing 'frontline' care for an individual with dementia (encompassing nurses, nursing assistants and direct care workers). There is evidence that the pressurised demands of caring for individuals with dementia may potentiate staff burnout and a decline in the quality of care that is provided (Ballard *et al.* 2000; Duffy *et al.* 2009).

Working with those with dementia appears to place more demands on psychological wellbeing of staff than caring for individuals with other illnesses (Edvardsson *et al.* 2009; Kimura *et al.* 2011): this possibly is a corollary of the highly variable behaviours manifested in dementia (such as challenging behaviour, hallucinations, and apathy and depression), and significant dependence on caregivers (Donaldson *et al.* 1998; Shua-Haim *et al.* 2001). The role has other intrinsic sources of stress notably high demands, time pressures, limited training and a lack of resources (Edvardsson *et al.* 2009; Maas *et al.* 2004; Sarabia-Cobo, 2015) as well as exposure to complaints by relatives, coping with the severe suffering, terminal illness, and death of care recipients (Richter *et al.* 2012). Notable amongst these are challenging behaviours, of which aggression

towards staff is prevalent (Bostrom *et al.* 2012; Lachs *et al.* 2013; Schmidt *et al.* 2012).

Job satisfaction

Formal caregivers, however, also report positive aspects of the work they undertake, particularly fulfilment derived from the alleviation of suffering (Coetzee & Klopper, 2010). In a study by Morrison and Korol, (2014), staff described marked job satisfaction, privileging the rewarding aspects of their job as caregivers, particularly feelings of effecting positive difference in the lives of the people they cared for. Thus job satisfaction may mitigate the impact of stressors and allow staff to continue in role. Indeed, job satisfaction has been deemed sufficiently important to feature in NICE (2009) guidelines for promoting health professional wellbeing at work, emphasising flexible working hours, sufficient training and managerial support to enhance job satisfaction, and improve recruitment and retention (Hayes *et al.* 2010; Karsh *et al.* 2005; Kloster *et al.* 2007).

Given a growing evidence base that absence of job satisfaction is associated with low quality of care and an increased absence from work (Burtson & Stichler, 2010; Castle *et al.* 2006;), its impact on performance has been increasingly explored. To date consensus regarding definition and operationalisation of job satisfaction has been difficult to achieve; it has been measured variously, with no agreed 'gold standard' (van Saane *et al.* 2003). Whilst there is no unanimity about the construct of job satisfaction, prominent models suggest it comprises intrinsic and extrinsic factors (DeShields Jr *et al.* 2005; Wallin *et al.* 2013). The two-factor theory, initially developed by Herzberg and colleagues (1959) (as cited in Wallin *et al.* 2013) suggests that job satisfaction can be enhanced or diminished by intrinsic factors such as responsibility and a sense of achievement (largely under personal control), and extrinsic (external, employer-directed) factors such as company policies, salary and working conditions. The intrinsic/extrinsic dichotomy also features in Taris and Feij's (2001) analysis of values underpinning satisfaction, describing intrinsic aspects as 'immaterial factors' such as autonomy, and extrinsic aspects as 'material factors' such as level of pay and opportunity for promotion. The two factor theory appears to provide a way to

categorise facets of job satisfaction and to acknowledge the roles of personal agency and appraisals, as well as the impact of organisation context and culture.

Thus far, detailed examination of what contributes to job satisfaction has tended to be partial, focusing on circumscribed factors (Wallin, 2012) although various studies have revealed some positive correlates with job satisfaction to include team work, peer support and the provision of supervision from management (Peterson *et al.* 2011; Spear *et al.* 2004;). Conversely negative correlates include low psychological wellbeing, work-related exhaustion, few promotional opportunities and staff shortages (Castle *et al.* 2006; Hasson & Arnetz, 2008). As applied to nursing staff in acute care Lu *et al.* (2012)'s systematic review identified a number of factors that were closely related to satisfaction including; work conditions and environment, psychological wellbeing, nature of the job role and organisational structure. However, no similar review has examined correlates of job satisfaction for those delivering dementia care.

Given the aforementioned difficulties presented when caring for someone with dementia and the attendant challenging behaviours, a review of the literature may illuminate the relationship between job satisfaction and dementia care work (Kimura *et al.* 2011; Kristiansen *et al.* 2006; Richter *et al.* 2012). High staff turnover amongst formal caregivers of older adults remains a concern and the World Health Organization and Alzheimer Disease International (2012) have advocated powerfully for a range of actions to improve the quality of care and services for people with dementia. These might be better targeted if factors enhancing satisfaction of the caregiver workforce can be identified

As yet there has been no comprehensive review examining potential predictors of job satisfaction of formal caregivers within dementia settings. Circumscribed and partial examination of job satisfaction in care assistants employed to deliver dementia care was reviewed by Manthorpe, (2014). This review noted an association between job satisfaction and enjoyment at work, better quality care of people with dementia and decreased staff turnover. The author contested that positive relationships were key in improving satisfaction; this included relationships with care recipients, other members of staff, and managers. However, this review was limited by a method which did not delineate database

interrogation, and focused on largely UK studies of care homes. Prompted by an initial examination of why people avoid or leave jobs in dementia care settings, Vernooji-Dassen *et al.* (2009) also reviewed the relationship between dementia care work and job satisfaction. Two of the strongest factors which appeared to be related to job satisfaction were Person Centred Care (PCC) and training. However, as this review failed to fully expand key search terms and with only one database interrogated, it provides very limited scrutiny of correlates and predictors of job satisfaction.

1.1 Aim of the literature review

Thus whilst job satisfaction in dementia care has been examined and reviewed, this has methodological limitations and has largely focused on its association with staff retention with little coverage of factors that may influence staff wellbeing when delivering formal care. Given the importance of job satisfaction and its potential psychological impact on caregivers and care recipients, further examination appears warranted. The purpose of this review is therefore to build on those of Manthorpe, (2014) and Vernooji-Dassen *et al.* (2009) and examine possible predictors of job satisfaction of formal caregivers who work within dementia care settings.

2. Method

A systematic review of the literature regarding the job satisfaction of formal caregivers in dementia settings was conducted by initially interrogating databases Psychinfo, Medline and CINAHL to assess published research in September 2015. These databases were chosen to ensure a range of psychological, medical and nursing articles and were supplemented by a search of the Cochrane Database of Systematic Reviews for any prior reviews.

Search terms

Table 1 shows the terms used in the search process, how they were combined and the use of truncations to capture all variances of a word. Terms were divided into four groups based on the aim of this review. They represented the original term selected and synonyms of dementia (group 1); caregivers (group 2); job (group 3) and satisfaction (group 4). These words were selected subsequent to

an initial scoping review of job satisfaction of caregivers in dementia since they emerged as key words that appeared in several abstracts and searches.

Table 1: Search terms

Group terms combined by 'AND'			
Group 1 – combined by 'OR'	Group 2 – combined by 'OR'	Group 3 – combined by 'OR'	Group 4 – combined by 'OR'
Dementia	Care*	Job	Satisfaction
Alzheimer*	Nurs*	Role	Quality
	Staff	Career	

Inclusion Criteria

Studies were included if a caregiver was defined as a formal or paid primary caregiver of individuals with dementia and worked within a setting which provided dementia care. Whilst numerous articles described or discussed job satisfaction, articles were only included if a measure of this concept was used.

Exclusion Criteria

Whilst searches were not limited to UK-based studies, language was restricted to English. As the review seeks to explore predictive factors of job satisfaction, qualitative studies were excluded as were experimental studies examining impact of interventions on job satisfaction. “Grey literature” publications were also excluded since they are not peer-reviewed.

Screening and selection

Articles retrieved were initially screened for salience to the current review question by scanning titles and abstracts for keywords. Eighty-six pertinent articles were initially identified, after duplicates (44 in total) were removed. Following preliminary reading of all 86 abstracts, 73 were excluded as they comprised; papers that were qualitative, reviews, or experimental. Thus 12 papers were deemed suitable for further review against the inclusion and exclusion criteria and full text versions obtained. Their reference lists were also examined to identify further relevant literature with two additional studies identified by this means. Of the 14 papers, only 11 were deemed eligible for final

inclusion in the current review. Three were excluded because participants were 'live in' domestic caregivers (N = 1) and explored satisfaction with care (N=1) and satisfaction with discharge planning (N = 1) rather than job satisfaction. Appendix B diagrammatically outlines the process by which articles were selected for the current review.

Data Extraction

Data for the 11 articles included in the current review was extracted using a data extraction form (Appendix C) which allowed the author to elicit relevant information from each article. The data extracted included author, title, year, country, aims, methodology, measures, statistical analysis, results and conclusions. Factors significantly associated with job satisfaction were noted in the data extraction process and grouped together for the results section of this report.

Quality Assessment

Since the papers in the review were predominantly cross sectional, a quality appraisal tool (Downs & Black, 1998), developed to appraise non-intervention studies, was utilised. This was deemed a good fit for purpose given its previous assessment for suitability in systematic reviews and has scope for tailoring as needed (Deeks *et al.* 2003).

Each of the studies in the current paper were assessed on four dimensions of the Downs and Black (1998) tool, modified by Thompson & McCabe (2012) for non-randomised and non-intervention based studies (Appendix D). Overall ratings were represented as a percentage score; Table 2 shows most studies were of moderate quality (>50% - <70%); two studies (Wallin *et al.* 2012; Zimmerman *et al.* 2005) had a high score (> 70%) (Thompson & McCabe, 2012). The four dimensions measured were: reporting, external validity, internal validity and study design. With regards to reporting, all studies demonstrated a good standard as they were explicit about their aims, detailed demographics and clearly explained their methodology and findings. The five studies which scored 5/5 for reporting stated actual probability values (e.g. 0.035 rather than <0.05). Each study scored high on internal validity as they used appropriate statistical tests (all studies were of cross sectional design and used either a correlational or regression analysis

Table 2: Quality appraisal scores

Study	Reporting (Score/5)	External Validity (Score/1)	Internal Validity (Score/3)	Study design (Score/2)	Quality score %
Brodaty <i>et al.</i> (2003)	5	0	2	0	64
Hirata and Harvath, (2015)	4	0	2	0	54
Isaksson <i>et al.</i> (2009)	5	0	2	0	64
Robison and Pillemer, (2007)	5	0	2	0	64
Sjogren <i>et al.</i> (2015)	5	0	2	0	64
te Boekhorst <i>et al.</i> (2008)	4	0	3	0	64
van Beek <i>et al.</i> (2011)	4	0	2	0	54
Wallin <i>et al.</i> (2012)	5	0	3	0	72
Willemse <i>et al.</i> (2012)	4	0	2	0	54
Willemse <i>et al.</i> (2015)	4	0	2	0	54
Zimmerman <i>et al.</i> (2005)	4	1	3	0	72

to examine relationships between variables) and the job satisfaction scales were standardised. Three studies scored 3/3 on internal validity as they acknowledged potential confounders such as participant demographics and adjusted their analysis accordingly; no other study adjusted for potential confounds. The table demonstrates that limitations in all of the studies lay in their external validity (with the exception of Zimmerman *et al.* 2005) and design. All of the reviewed studies have a zero score for design as they are cross-sectional which precluded examination of causal relationships and one of the questions in the tool is not relevant as it refers to experimental designs.

3. Results

For the purpose of overview and synthesis, the reviewed papers have been organised into five non-mutually exclusive groups which arise from the focus and findings of the studies. Due to the heterogeneity of the studies it was not suitable to conduct a meta-analysis, thus data was synthesised using a narrative perspective. The groups comprise papers focusing on: person-centred care (PCC), setting, support, aggression, and caregiver distress. Measurements of job satisfaction are also explored. A summary of the 11 articles selected for review can be found in Appendix E.

Demographic sample

The studies were conducted across five different countries and the number of participants ranged from 137 to 1169. The participants included qualified (i.e. nurses) and non-qualified (i.e. nursing assistants) staff; the variety of settings in which participants worked included nursing homes, special care units for people with dementia and residential homes.

Measures of Job Satisfaction

It is unclear if there is a shared understanding and operationalisation of job satisfaction since definition of the term was only provided in one of the papers (Wallin *et al.* 2012). The authors adopted Locke's (1976) definition that job satisfaction is a pleasurable state arising from the appraised experience within the nurses' role. No other articles provided an explicit definition. The lack of clarity regarding a definition of job satisfaction is further complicated by the variety of

outcome instruments which were used to measure the concept. Eight scales were used across the eleven studies.

Six of the eight measurement tools (Table 3) have been drawn together to illustrate the variety of dimensions assessed; they each have numerous individual items within separate dimensions and to identify and compare all of the items is beyond the scope of this paper. Two measures were omitted from the table (the job satisfaction subscale of the Leiden Quality of Work Questionnaire (LQWQ) (van der Doef & Maes, 1999) and the Generic Job Satisfaction Scale (Macdonald & MacIntyre, 1997)) since they comprised a relatively small number of questions (4-10 items) and were not grouped into different dimensions as the other measures were. In all, 26 separate dimensions are used, demonstrating marked variation in measurement of job satisfaction. As can be seen in Table 3, items within the measures show little overlap, suggesting little shared identity of the concept. The two most common dimensions comprise support (four instruments) and patient contact (three instruments); a number of dimensions such as promotion opportunity and salary are evident in only one measure. The diversity of dimensions is unsurprising given the lack of consensus about what job satisfaction encompasses.

Person-centred care

In four of the studies the relationship between PCC and job satisfaction was explicitly examined. PCC encompasses the caregivers' attitude and approach to their work not just a focus on the disease, and embraces the care recipients' personality, experiences and relationships (Epp, 2003). In the studies, PCC was measured as an ethos i.e. planning care based on individual needs and offering care recipients' choice. Examining the relationship between staff characteristics, work environment and PCC in nursing staff, Sjogren *et al.* (2005) found job satisfaction to be significantly and positively correlated with PCC ($r = 0.65$, $p < 0.001$) and a significant variable ($\beta = 0.135$, $p < 0.001$) in regression with two other factors (psychosocial climate and job strain) where PCC was the dependant variable. Job strain accounted for most variance, whilst job satisfaction accounted for the least. The authors concluded that a more PCC approach taken by staff was associated with higher job satisfaction, lower job strain and more

Table 3: Comparison of dimensions across job satisfaction measures

Dimensions which are measured	Measures					Psychosocial Aspects of Job satisfaction Questionnaire
	Job Satisfaction Questionnaire	Swedish Satisfaction with Nursing Care and Work Assessment Scale (SNCW)	Staff Experience Working with Demented Residents.	Kahana's Measure of Job Satisfaction of formal caregivers	Maastricht Work Satisfaction Scale for Healthcare (MASGZ)	
Autonomy in work	x	x				
Competence in work	x					
Emotions in work	x					
Initiative in work	x					
Relationships/Support	x			x	x	x
Professional growth		x				x
Information given to patients		x				
Comfort at work		x				
Quality of care		x			x	
Patient contact		x	x		x	
My work related knowledge		x				
Positive attitude to my work		x				
The organisation			x			
My expectations of work			x			
Working environment			x			
Other expectations of me			x			x
Feedback			x			
Salary				x		
Job content				x		
Promotion opportunity					x	
Task clarity					x	
Workload						x
Criticism						x
Internal motivation						x
External motivation						x
Position in group						x

supportive environments. As PCC was the dependant variable it should be noted that whilst a significant association was found between PCC and job satisfaction, the results suggest that greater job satisfaction is a possible predictor of higher levels of PCC and not the other way around. Similar results were described by Wallin *et al.* (2012) who examined variables associated with general job satisfaction and satisfaction with nursing-care provision (context-specific job satisfaction). PCC had a significant relationship with both general job and context-specific satisfaction ($\beta = 0.24$, $p < 0.001$ & $\beta = 0.21$, $p < 0.001$ respectively). In their study examining staff's person-centeredness in dementia care, Willemse *et al.* (2015) also found a significant positive relationship between staff who took a PCC approach and their levels of job satisfaction ($\beta = 0.07$, $P \leq 0.05$). The authors also noted that the relationship between supervisor support and job satisfaction ($\beta = 0.25$, $p \leq 0.01$) were stronger for nurses with a strong person-centred attitude compared to those with a less person-centred attitude. Further to this Zimmerman *et al.* (2005) explored associations between attitudes of healthcare staff, job satisfaction and found a significant positive association between PCC and job satisfaction ($r = 0.28$, $p < 0.01$). Each of these studies demonstrated that staff who held a positive or more person centred attitude towards the work they did reported higher levels of job satisfaction.

Setting

In two of the studies there was an examination of the setting in which caregivers worked and how this related to job satisfaction. Differences in staff satisfaction between Special Care Units (SCUs) for dementia care and non-SCUs was assessed by Robison and Pillemer, (2007). An initial analysis revealed reported job satisfaction as higher on SCUs compared to non-SCUs. When relationships with co-workers and managers were added to a regression model the size of the Beta value for the SCU advantage compared to non SCU's was halved ($\beta = -1.262$, $p < .001$ to $\beta -.601$, $p = .047$) suggesting that interpersonal relationships with other staff and managers were predictive of levels of job satisfaction irrespective of setting.

Te Boekhorst *et al.* (2008) investigated job satisfaction and burnout as a function of group living homes or traditional nursing homes. The latter offered care based

on a hospital model whereas group living homes operated more 'home like' environment. Initial analysis of satisfaction suggested higher levels for those nursing staff in the group living homes than staff in traditional nursing homes. Once job demands, job control and colleague support were added into a regression model, the relationship between type of home and job satisfaction dropped below significance. The magnitude of the Beta value for the group home benefit was reduced ($\beta = 0.29$, $p < .001$ to $\beta 0.07$, *non-significant*), and suggested that the three additional factors mediated the relationship between setting type and job satisfaction. Unlike PCC, the results for settings as a possible predictor of job satisfaction appear more equivocal and require detailed understanding of other factors within a work setting.

Types of support

Two studies explored the relationship between job satisfaction and support that caregivers received at work. Willemse *et al.* (2012) examined the impact of peer or supervisor support on job satisfaction, demonstrating that low levels of peer ($\beta = 0.28$ $p < .001$) and supervisor ($\beta = 0.39$, $p < .001$) support were associated with lower levels of job satisfaction. When these variables were added into a regression analysis with job demand, the results showed that interactions between high demands and low levels of peer ($\beta = -.02$) and supervisor ($\beta = -.04$) support were associated with lower levels of job satisfaction, yet neither result was found to be significant. In the second study, Van Beek *et al.* (2008) explored the relationship between job satisfaction and peer support across a number of dementia care units with significant association found between satisfaction and the number of staff on the unit ($\beta = 0.006$, $p \leq 0.05$): units with fewer staff were associated with higher levels of satisfaction, communication across staff was easier in smaller than larger groups. The study also examined density of communication (higher density describing greater staff interaction and reciprocal support), the addition of this variable to the regression model was also found to positively correlate with job satisfaction, however this was not significant ($\beta = 0.352$, $p \leq 0.10$). As with the studies which examined different settings, the results for support are ambiguous.

Caregiver distress

Four of the studies examined the relationship between psychological distress (such as stress and emotional exhaustion) and job satisfaction. Brodaty *et al.* (2003) found a significant positive correlation between job satisfaction and stress ($r = 0.141$, $p = 0.046$): the authors also noted that staff attitudes towards care recipients were negatively associated with lower levels job satisfaction ($r = -0.192$, $p = 0.004$). Those staff with negative attitudes towards residents had lower job satisfaction. Similar results were described by Willemse *et al.* (2015), finding staff who reported a more person-centred attitude disclosed high emotional exhaustion ($\beta = 0.13$, $p \leq 0.05$) yet high levels of job satisfaction ($\beta = 0.07$, $p \leq 0.05$). By contrast, two studies identified a negative relationship between job satisfaction and distress. Zimmerman *et al.* (2005) found a significant association between stress and job satisfaction ($r = -0.24$, $p < 0.01$). Similarly, low levels of general satisfaction were associated with higher levels of worry ($\beta = -0.20$, $p = 0.001$), and low context-specific job satisfaction with greater sadness and depression ($\beta = -0.13$, $p = 0.013$) in Wallin *et al.*'s. (2012) study. Both studies suggested that staff exposed to higher levels of stress experienced lower job satisfaction. However, as all four studies reported small correlations - despite their results being significant - the results should be interpreted with caution. The findings may have little meaning as small correlation coefficients indicate a weak association between job satisfaction and carer distress. The contradictory outcomes of these studies will be considered further in the discussion.

Aggression

Two studies explored the relationship between job satisfaction and clients' aggression. Hirata and Harvath, (2015) examined the relationship between caregiver's exposure to aggression and job satisfaction, revealing a significant negative correlation ($r = -0.21$, $p < 0.01$). However, numerous other factors unmeasured in this study such as levels of support and opportunities for promotion could contribute. The association between aggression and job satisfaction was also explored by Isaksson *et al.* (2009) who focused on the difference between care units with a high prevalence (HPW) of aggression and

those with a low prevalence (LPW). After a test for multi-collinearity, discrimination analysis demonstrated that job satisfaction was one of five variables which significantly differed between HPW's and LPW's. Those staff who worked in HPW's reported significantly lower levels of job satisfaction ($F = 4.35$, $p = 0.046$). Staff in the HPW's also reported higher demands and greater dissatisfaction with their working environment. Based on the results of these studies it is difficult to draw conclusions on the predictive nature of aggression in isolation since its impact has not been partialled out from other environmental confounds.

3.1 Methodological limitations

Significant methodological issues were identified in the reviewed studies and results should thus be interpreted cautiously. Authors did not utilise a shared construct of what job satisfaction comprises and scales used examined different facets of job satisfaction. The heterogeneity of outcome measures reported, with little recourse to underpinning theory using variable numbers of items, constrains the completeness of a synthesis. In addition to the instruments used in these studies, there are numerous other questionnaires used to measure job satisfaction (van Saane *et al.* 2003). The difficulty in having available a large pool of the types of measures is that it further complicates the problem of trying to develop a universal definition or model of job satisfaction (Pol-Grevelink *et al.* 2012).

All studies were of a cross sectional design, precluding examination of the causal relationship between these factors and job satisfaction. External validity and general applicability of the findings of the studies is limited because seven of the studies used opportunistic samples, potentially unrepresentative of all formal caregivers. Indeed, Morrison and Korol, (2014) argues that nurses who are most resilient to the demands of care work are over-represented in research findings. Three studies (Robison & Pillemer, 2007; Willemse *et al.* 2012; Willemse *et al.* 2015) used data that was sampled randomly, but collected from previously completed research. Whilst a randomised approach allows for a more representative sample, given the high turnover rate of staff in dementia care (Vernooji-Dassen *et al.* 2009), the sample recruited in the older studies may not

have been typical of caregivers at the time the later studies were conducted. Zimmerman *et al.* (2005) used a random sample collected for their study which may improve the generalisation of their results.

Further difficulties in generalisability emerge from the settings and locations in which the studies were completed. The elicited studies were completed in five different countries undermining direct comparison of results due to cultural differences in how people with dementia are viewed (Emilsson, 2011; Cipriani & Borin 2014) and worldwide differences of services available to people with dementia (Guerra *et al.* 2011). To illustrate this point, in the UK alone, care homes for older adults differ in staffing levels, composition (extent of training and seniority) and environment (Manthorpe, 2014), compromising comparison of small specialised units with large nursing homes (Castle, 2008). Furthermore, whilst all studies included staff who worked in settings which provided care for people with dementia, only Zimmerman *et al.* (2005) detailed how many residents had received a diagnosis (53.2%). The remaining 10 studies did not stipulate how many residents were diagnosed with dementia, although Isaksson *et al.* (2009) and Sjogren *et al.* (2015) detailed residents who were rated as having a cognitive impairment equivalent to dementia (79.3% & 88% respectively). Therefore, the findings of each study and their implications in dementia care should be interpreted with caution.

4. Discussion

The current review aimed to identify predictive factors of job satisfaction reported by formal caregivers working within dementia settings. The 11 studies elicited for this review were overall of moderate quality and presented a number of limitations. However, from this circumscribed body of research there appeared a number of factors which were associated with job satisfaction in dementia care - how an individual approaches their work, the setting they work in, the support they receive, their experience of challenging behaviour and their psychological wellbeing - and merit further investigation.

4.1 Discussion of results

In each of the studies examining PCC, a positive and significant correlation with job satisfaction was found, understandable given that care recipients are valued and viewed more benignly (Epp, 2003). The current findings resonate with other reviews notably Vernooji-Dassen *et al.* (2009), who also reported that patient-centeredness in dementia care was associated with increased levels of job satisfaction; however, they did not speculate on what the mechanism of this may be. Similarly, results have been reported for nursing staff delivering care in non-dementia care context; a review by Pol-Grevelink *et al.* (2012) revealed PCC to have positive impact on job satisfaction; although, the findings were limited due to methodological issues of the studies such as the utilisation of a variety of scales, not dissimilar to the current review. The positive association between PCC and job satisfaction could arise from a number of reasons such as investing in a reciprocal relationship with the care recipient (Ericson-Lidman *et al.* 2014) and giving staff a feeling of competence (Mullan & Sullivan, 2015), both likely to be rewarding to caregivers.

Two studies in this review revealed satisfaction significantly differed dependant on type of setting (Robison and Pillemer, 2007; Te Boekhorst *et al.* 2008). Similarly Spear *et al.* (2004) noted a difference in job satisfaction of mental health staff (such as nurses and psychiatrists) working in community and ward settings. Although, other factors such as teamwork and stress were also associated with levels of job satisfaction and the relationships between each of these variables was not fully explored. Interestingly, in the two studies from the current review the significance of the relationships between setting type and job satisfaction reduced when support was added to the analysis as a variable. Both sets of authors suggested that higher levels of satisfaction were associated with support regardless of the setting. Indeed, in the two studies which examined support, it was associated with higher levels of job satisfaction (Van Beek *et al.* 2011; Willemse *et al.* 2012). The results echo findings from other dementia-based literature (Manthorpe, 2014) and non-dementia healthcare settings (Peterson *et al.* 2011; Sellgren *et al.* 2008), all noting that team work, peer support and the provision of supervision correlate positively with job satisfaction. The positive

impact of support on job satisfaction may arise from the sharing of difficulties, joint training and relating socially outside of the working environment (Kimura *et al.* 2011; Manthorpe, 2014). However, as with the studies which explored settings, once other factors such as job demands were added into the models the results were no longer significant.

The ambiguity of findings in this review was further highlighted in the studies examining psychological distress. Surprisingly, given an extensive literature documenting the impact of care work on levels of stress, burnout and affect (Ballard *et al.* 2000, Duffy *et al.* 2009, Edvardsson *et al.* 2009), only four studies were elicited examining the relationship between distress and job satisfaction. Given the negative impact of care work on psychological wellbeing, lower levels of satisfaction might be an anticipated correlate of distress as was found in two of the studies (Wallin *et al.* 2012; Zimmerman *et al.* 2005). Indeed, similar results have been demonstrated in other healthcare settings (Castle *et al.* 2006; Hasson & Arnetz, 2008; Healy & McKay, 2000). However, two studies in this review demonstrated that high levels of distress were not associated with lower levels of job satisfaction (Brodaty *et al.* 2003; Willemse *et al.* 2015). Like job satisfaction, caregiver distress has been defined in numerous ways (Lee *et al.* 2006) and the impact of stress can vary dependant on how a person adapts to a given situation (Lazarus & Folkman, 1984); this may partly explain the difference of findings between the four studies as distress was measured in various ways (stress, strain, emotional exhaustion, worry and depression). Interestingly, despite the differing levels of distress, three of the studies found that PCC was associated with higher job satisfaction (Wallin *et al.* 2012; Willemse *et al.* 2015; Zimmerman *et al.* 2005) and Brodaty *et al.* (2003) found that positive attitudes towards residents was associated with higher levels of job satisfaction. It seems the relationship between satisfaction and distress may not be linear, indeed the mixed findings reflect that commitment to care such as PCC can enhance satisfaction but may render the carer vulnerable to distress such as burnout or compassion fatigue (Coetzee & Klopper, 2010; Morrison & Korol, 2014).

Only two studies (Hirata & Harvath, 2015; Isaksson *et al.* 2009) were elicited examining the relationship between client aggression and job satisfaction, unusual given the already noted prevalence of challenging behaviour in dementia

(Lachs *et al.* 2013; Schmidt *et al.* 2012; Skovdahl *et al.* 2003). Both studies found that experience of higher levels of aggression was associated with lower job satisfaction. However, both studies acknowledged that the relationship between low levels of job satisfaction and aggression may have been influenced by other factors that were not considered, such as support from colleagues and previous experience of challenging behaviour. One could argue that job satisfaction in relation to challenging behaviour is based on a continuum of interacting factors; indeed, Kristiansen *et al.* (2006) found satisfaction fluctuated between 'building up' and 'breaking down' caregivers when exposed to aggressive behaviour. Despite the negative impact of aggression (such as feelings of humiliation), staff continued to work with residents because it was balanced out by the positive impact of peer support on psychological well-being (Kristiansen *et al.* 2006). Given the high prevalence of challenging behaviour in dementia and the small number of papers elicited examining its relationship to job satisfaction, further exploration is merited.

On the basis of the diverse studies elicited and their use of different constructs and measures, synthesis is difficult. Primarily this stems from an ongoing lack of consensus on what constitutes job satisfaction and how it is operationalised. As job satisfaction and its constituent elements are insufficiently defined, precision regarding predictive factors is difficult; there were disparate and partial findings in the studies based on weak associations which disappeared when more complex models were offered. Similar findings have been reported in wider healthcare literature such as Lu *et al.* (2012) in their review of job satisfaction in qualified general nurses working in acute care hospitals. The authors highlighted the complexity of job satisfaction and the lack of a definitive causal model for it. Although many causal models of job satisfaction have been proposed, they require further testing to strengthen the suggested contributions of different factors on this construct (Lu *et al.* 2012). Furthermore, Caers *et al.* (2008) noted the difficulties in trying to provide a clear conclusion of job satisfaction in Community Nurses due to variety of scales that were used in the studies they reviewed. These findings are also echoed in non-healthcare literature; in their review of job satisfaction in the business sector, Dugguh and Dennis, (2014) described the complexity of job satisfaction arising from a number of contributing

factors (including supervision, interpersonal relationships and salary) and suggested further investigation of the concept. Thus the difficulties noted in the current review are not confined to dementia care - as was noted by Manthorpe, (2014) - and reflect a wider issue as to what constitutes job satisfaction.

4.2 Future

To progress research in this area there needs to be greater agreement on the construct of job satisfaction and consequent measures that can be used within dementia care. Studies with more rigorous methodologies (such as detailed information on people with a diagnosis of dementia) utilising a shared concept and measure of job satisfaction may at least begin to make comparison across studies a little clearer.

It could be argued that different facets of job satisfaction are reflected in Maslow's (1943) hierarchy of needs and that in order to be satisfied with one's work, one would need to fulfil their needs at all levels such as security (having a secure job), social (receiving support at work) and esteem (receiving praise and recognition) (Baslevent & Kirmanoglu, 2013). Maslow argued that the most basic needs had to be fulfilled first before the next level could be met (Harrigan & Commons, 2015). On this basis it seems that going to the source and finding out from caregivers what is important to them with regards to job satisfaction is an appropriate starting point. One way to address this could be to undertake meta-synthesis of qualitative research; in such studies caregivers have been interviewed to try and elicit their understanding of job satisfaction (Ericson-Lidman *et al.* 2014; Kristiansen *et al.* 2006; Ryan *et al.* 2004). A meta-synthesis could be conducted to identify the most common themes relating to job satisfaction in dementia care and possibly enable the development of a scale relevant to this area of care. As Morse, (2003) explains, qualitative methodology can be useful when a context is poorly understood, the definition of a domain is vague or a phenomenon needs to be re-examined.

4.3 Review limitations

This review is strengthened by a clearly described systematic search strategy, a range of different and salient databases encompassing psychological, nursing and medical studies, and quality appraisal of the chosen studies. Nevertheless, the review should also be considered within the context of its limitations. Some

similarities with the findings in other healthcare literature were noted; however, as this review focused on dementia care, caution needs to be taken regarding its application to other care settings.

Due to the heterogeneity of the studies a meta-analysis could not be conducted and a narrative synthesis was necessary; therefore, an estimate of the overall findings could not be calculated. Furthermore, the review contained a combination of studies that examined associative or predictive factors and their relationship to job satisfaction, thus overall predictability of the factors is limited – further hindered by the cross sectional nature of the studies. The factors identified in this review (PCC, support, setting type, caregiver distress and aggression) are not exhaustive of elements that may contribute to job satisfaction of dementia caregivers; reviews exploring other types of studies such as qualitative and experimental may identify alternative factors. Additionally, the literature was examined collectively rather than differentiated by type of dementia, setting or staff role (with so few studies identified as eligible this may be difficult to undertake). It could be contended that a more homogenous focus, for example an emphasis on job satisfaction within specialised dementia units, may have better highlighted the predictors of job satisfaction in a particular area of dementia care (this too may be limited by the number of appropriate studies available).

4.4 Implications

The results from this review and other literature suggest there are factors that services can be aware of that may enhance staff satisfaction such as providing supervisory support and encouraging PCC. This is relevant in a clinical setting because increased satisfaction may enhance quality of care for people with dementia (Castle *et al.* 2006; Burtson & Stichler, 2010). This will possibly have to be encouraged from an organisational level, for example, it has been argued that those in managerial roles are in a vital position to foster a PCC ethos and maintain this through on-going discussions with their staff (Brooker, 2007). However, given the heterogeneity of the studies conclusions are limited – as yet there is circumscribed evidence. This in itself is an important consideration as policy makers need guidance from empirical evidence in order to allocate limited resources (Acton & Kang, 2001), and further research appears priority to inform

future clinical practice. Gaining a clearer understanding of job satisfaction in caregivers of people with dementia will hopefully lead to the development of models that can be applied clinically.

4.5 Conclusion

The findings of this review are consistent with other studies in dementia and non-dementia care work which demonstrate that PCC, setting type, support and levels of psychological distress are possible predictors of levels of job satisfaction. Given the limitations of the studies reviewed it is difficult to draw a clear conclusion on the association between these factors and job satisfaction. This is further complicated by the lack of an unambiguous definition of the concept and a variety of scales used to measure it. A continued exploration into job satisfaction is essential. Holding in mind the aim of supporting caregivers as a key resource, an examination of the factors they themselves deem are important in influencing their levels of satisfaction is necessary.

5. References

- Acton, G. J., & Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. *Research in Nursing & Health*, 24(5), 349-360.
- Åström, S., Nilsson, M., Norberg, A., Sandman, P. O., & Winblad, B. (1991). Staff burnout in dementia care—Relations to empathy and attitudes. *International Journal of Nursing Studies*, 28(1), 65-75.
- Ballard, C., Lowery, K., Powell, I., O'Brien, J., & James, I. (2000). Impact of behavioral and psychological symptoms of dementia on caregivers. *International Psychogeriatrics*, 12(S1), 93-105.
- Başlevent, C., & Kirmanoğlu, H. (2013). Do Preferences for Job Attributes Provide Evidence of 'Hierarchy of Needs'?. *Social Indicators Research*, 111(2), 549-560.
- Boström, A. M., Squires, J. E., Mitchell, A., Sales, A. E., & Estabrooks, C. A. (2012). Workplace aggression experienced by frontline staff in dementia care. *Journal of Clinical Nursing*, 21(9-10), 1453-1465.
- *Brodaty, H., Draper, B., & Low, L. F. (2003). Nursing home staff attitudes towards residents with dementia: Strain and satisfaction with work. *Journal of Advanced Nursing*, 44(6), 583-590.
- Brooker, D. (2007). *Person-centred dementia care: Making Services Better*. London: Jessica Kingsley Publishers.
- Burtson, P. L., & Stichler, J. F. (2010). Nursing work environment and nurse caring: Relationships among motivational factors. *Journal of Advanced Nursing*, 66(8), 1819-1831.
- Caers, R., Du Bois, C., Jegers, M., De Gieter, S., De Cooman, R., & Pepermans, R. (2008). Measuring community nurses' job satisfaction: Literature review. *Journal of Advanced Nursing*, 62(5), 521-529.
- Castle, N. G. (2008). Nursing home caregiver staffing levels and quality of care a literature review. *Journal of Applied Gerontology*, 27(4), 375-405.

- Castle, N. G., Degenholtz, H., & Rosen, J. (2006). Determinants of staff job satisfaction of caregivers in two nursing homes in Pennsylvania. *BMC Health Services Research*, 6(1), 60.
- Cipriani, G., & Borin, G. (2014). Understanding dementia in the sociocultural context: A review. *International Journal of Social Psychiatry*, 61(2), 198-204.
- Coetzee, S. K., & Klopper, H. C. (2010). Compassion fatigue within nursing practice: A concept analysis. *Nursing & Health Sciences*, 12(2), 235-243.
- Deeks, J. J., Dinnes, J., D'amico, R., Sowden, A. J., Sakarovitch, C., Song. *et al.* (2003). Evaluating non-randomised intervention studies. *Health Technology Assessment*, 7(27), 1-179.
- DeShields Jr, O. W., Kara, A., & Kaynak, E. (2005). Determinants of business student satisfaction and retention in higher education: Applying Herzberg's two-factor theory. *International Journal of Educational Management*, 19(2), 128-139.
- Donaldson, C., N. Tarrier, and A. Burns. (1998). Determinants of carer stress in Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 13(4), 248-256.
- Downs, S. H., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health*, 52(6), 377-384.
- Duffy, B., Oyeboode, J. R., & Allen, J. (2009). Burnout among care staff for older adults with dementia: The role of reciprocity, self-efficacy and organizational factors. *Dementia*, 8(4), 515-541.
- Dugguh, S., & Dennis, A. (2014). Job satisfaction theories: Traceability to employee performance in organizations. *Journal of Business and Management*, 16(5), 11-18.
- Edvardsson, D., Sandman P. O., Nay, R., & Karlsson, S. (2009). Predictors of job strain in residential dementia care nursing staff. *Journal of Nursing Management*, 17(1), 59-65.

- Epp, T. D. (2003). Person-centred dementia care: A vision to be refined. *The Canadian Alzheimer Disease Review*, 5(3), 14-19.
- Ericson-Lidman, E., Larsson, L. L. F., & Norberg, A. (2014). Caring for people with dementia disease (DD) and working in a private not-for-profit residential care facility for people with DD. *Scandinavian Journal of Caring Sciences*, 28(2), 337-346.
- Emilsson, U. M. (2011). The staff's view on dementia and the care in three cultures: A qualitative study in France, Portugal and Sweden. *Dementia*, 11(1) 31-47.
- Engström, M., Ljunggren, B., Lindqvist, R., & Carlsson, M. (2006). Staff satisfaction with work, perceived quality of care and stress in elderly care: Psychometric assessments and associations. *Journal of Nursing Management*, 14(4), 318-328.
- Gaugler, J. E. (2005). Family involvement in residential long-term care: A synthesis and critical review. *Aging & Mental Health*, 9(2), 105-118.
- Guerra, M., Ferri, C. P., Fonseca, M., Banerjee, S., & Prince, M. (2011). Helping carers to care: The 10/66 dementia research group's randomized control trial of a caregiver intervention in Peru. *Revista Brasileira de Psiquiatria*, 33(1), 47-54.
- Hagen, B. (2001). Nursing home placement: Factors affecting caregivers' decisions to place family members with dementia. *Journal of Gerontological Nursing*, 27(2), 44.
- Hallberg, I. R., Hansson, U. W., & Axelsson, K. (1993). Satisfaction with nursing care and work during a year of clinical supervision and individualized care. Comparison between two wards for the care of severely demented patients. *Journal of Nursing Management*, 1(6), 297-307.
- Harrigan, W. J., & Commons, M. L. (2015). Replacing Maslow's needs hierarchy with an account based on stage and value. *Behavioral Development Bulletin*, 20(1), 24.

Hasson, H., & Arnetz, J. E. (2008). Nursing staff competence, work strain, stress and satisfaction in elderly care: A comparison of home-based care and nursing homes. *Journal of Clinical Nursing*, 17(4), 468-481.

Hayes, B., Bonner, A. N. N., & Pryor, J. (2010). Factors contributing to nurse job satisfaction in the acute hospital setting: A review of recent literature. *Journal of Nursing Management*, 18(7), 804-814.

Healy, C. M., & McKay, M. F. (2000). Nursing stress: The effects of coping strategies and job satisfaction in a sample of Australian nurses. *Journal of Advanced Nursing*, 31(3), 681-688.

Heru, A. M., Ryan, C. E., & Iqbal, A. (2004). Family functioning in the caregivers of patients with dementia. *International journal of Geriatric Psychiatry*, 19(6), 533-537.

*Hirata, H., & Harvath, T. A. (2015). The relationship between exposure to dementia-related aggressive behaviour and occupational stress among Japanese care workers. *Journal of Gerontological Nursing*, 41(4), 38.

*Isaksson, U., Åström, S., Sandman, P. O., & Karlsson, S. (2009). Factors associated with the prevalence of violent behaviour among residents living in nursing homes. *Journal of Clinical Nursing*, 18(7), 972-980.

Karsh, B., Booske, B. C., & Sainfort, F. (2005). Job and organizational determinants of nursing home employee commitment, job satisfaction and intent to turnover. *Ergonomics*, 48(10), 1260-1281.

Kimura, H., Tamoto, T., Kanzaki, N., & Shinch, K. (2011). Burnout and characteristics of mental health of caregivers of elderly dementia patients. *Journal of Rural Medicine*, 6(2), 47-53.

Kloster, T., Høie, M., & Skår, R. (2007). Nursing students' career preferences: A Norwegian study. *Journal of Advanced Nursing*, 59(2), 155-162.

Kristiansen, L., Hellzén, O., & Asplund, K. (2006). Swedish assistant nurses' experiences of job satisfaction when caring for persons suffering from dementia and behavioural disturbances. An interview study. *International Journal of Qualitative Studies on Health and Well-being*, 1(4), 245-256.

- Lachs, M. S., Rosen, T., Teresi, J. A., Eimicke, J. P., Ramirez, M., Silver, S. *et al.* (2013). Verbal and physical aggression directed at nursing home staff by residents. *Journal of General Internal Medicine*, 28(5), 660-667.
- Lazarus, R.S. & Folkman, S. (1984). *Stress, Appraisal and Coping*. New York: Springer Publishing Company.
- Lee, H. S., Kim, D. K., & Kim, J. H. (2006). Stress in caregivers of demented people in Korea—A modification of Pearlin and colleagues' stress model. *International Journal of Geriatric Psychiatry*, 21(8), 784-791.
- Locke, E. A. (1976). The nature and causes of job satisfaction. In M. D. Dunnette (ed.) *Handbook of Industrial and Organizational Psychology* (pp.1297-1343). Chicago: Rand McNally.
- Lu, H., Barriball, K. L., Zhang, X., & While, A. E. (2012). Job satisfaction among hospital nurses revisited: A systematic review. *International Journal of Nursing Studies*, 49(8), 1017-1038.
- Maas, M. L., Reed, D., Park, M., Specht, J. P., Schutte, D., Kelley, L. S. *et al.* (2004). Outcomes of family involvement in care intervention for caregivers of individuals with dementia. *Nursing Research*, 53(2), 76-86.
- Macdonald, S., & MacIntyre, P. (1997). The generic job satisfaction scale: Scale development and its correlates. *Employee Assistance Quarterly*, 13(2), 1-16.
- Manthorpe, J. (2014). Enjoying the front-line of dementia care: An integrative analysis of what care home staff report makes them happy at work. *Working with Older People*, 18(4), 167-175.
- Maslow, A.H. (1943). A theory of human motivation. *Psychological Review*, 50(4), 370-396.
- Morrison, K. B., & Korol, S. A. (2014). Nurses' perceived and actual caregiving roles: Identifying factors that can contribute to job satisfaction. *Journal of Clinical Nursing*, 23(23-24), 3468-3477.
- Morse, J. (2003). A review committee's guide for evaluating qualitative proposals. *Qualitative Health Research*, 13(6), 833-851.

Mullan, M. A., & Sullivan, K. A. (2015). Positive attitudes and person-centred care predict of sense of competence in dementia care staff. *Aging & Mental Health*, 20(4), 407-414.

National Institute for Health and Clinical Excellence (NICE). (2009). *Promoting mental wellbeing at work*. Retrieved 9th October 2015 from www.nice.org.uk/guidance/ph22.

Peterson, J., Hall, L. M., O'Brien-Pallas, L., & Cockerill, R. (2011). Job satisfaction and intentions to leave of new nurses. *Journal of Research in Nursing*, 16(6), 536-548.

Pol-Grevelink, A., Jukema, J. S., & Smits, C. H. M. (2012). Person-centred care and job satisfaction of caregivers in nursing homes: A systematic review of the impact of different forms of person-centred care on various dimensions of job satisfaction. *International Journal of Geriatric Psychiatry*, 27(3), 219-229.

Richter, J., Åström, S., & Isaksson, U. (2012). Personality characteristics of staff in elderly care—A cross-cultural comparison. *Issues in Mental Health Nursing*, 33(2), 96-100.

*Robison, J., & Pillemer, K. (2007). Job satisfaction and intention to quit among nursing home nursing staff: Do special care units make a difference? *Journal of Applied Gerontology*, 26(1), 95-112.

Ryan, T., Nolan, M., Enderby, P., & Reid, D. (2004). 'Part of the family': Sources of job satisfaction amongst a group of community-based dementia care workers. *Health & Social Care in The Community*, 12(2), 111-118.

Sarabia-Cobo, C. M. (2015). Heart Coherence: A New Tool in the Management of Stress on Professionals and Family Caregivers of Patients with Dementia. *Applied Psychophysiology and Biofeedback*, 40(2), 75-83.

Sellgren, S. F., Ekvall, G., & Tomson, G. (2008). Leadership behaviour of nurse managers in relation to job satisfaction and work climate. *Journal of Nursing Management*, 16(5), 578-587.

Schmidt, S. G., Dichter, M. N., Palm, R., & Hasselhorn, H. M. (2012). Distress experienced by nurses in response to the challenging behaviour of residents—

evidence from German nursing homes. *Journal of Clinical Nursing*, 21(21-22), 3134-3142.

Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry*, 12(3), 240-249.

Shua-Haim, Joshua R., Todd Haim, Yong Shi, Yen-Hong Kuo, and Juanita M. Smith. (2001). Depression among Alzheimer's caregivers: Identifying risk factors. *American Journal of Alzheimer's Disease and Other Dementias*, 16(6), 353-359.

*Sjögren, K., Lindkvist, M., Sandman, P. O., Zingmark, K., & Edvardsson, D. (2015). To what extent is the work environment of staff related to person-centred care? A cross-sectional study of residential aged care. *Journal of Clinical Nursing*, 24(9-10), 1310-1319.

Skovdahl, K., Kihlgren, A. L., & Kihlgren, M. (2003). Different attitudes when handling aggressive behaviour in dementia--narratives from two caregiver groups. *Aging & Mental Health*, 7(4), 277-286.

Spear, J., Wood, L., Chawla, S., Devis, A., & Nelson, J. (2004). Job satisfaction and burnout in mental health services for older people. *Australasian Psychiatry*, 12(1), 58-61.

Taris, R., & Feij, J. (2001). Longitudinal examination of the relationship between supplies-values fit and work outcomes. *Applied Psychology*, 50(1), 52-80.

*te Boekhorst, S., Willemse, B., Depla, M. F., Eefsting, J. A., & Pot, A. M. (2008). Working in group living homes for older people with dementia: The effects on job satisfaction and burnout and the role of job characteristics. *International Psychogeriatrics*, 20(05), 927-940.

Thompson, L., & McCabe, R. (2012). The effect of clinician-patient alliance and communication on treatment adherence in mental health care: A systematic review. *BMC Psychiatry*, 12(1), 87.

*van Beek, A. P., Wagner, C., Spreeuwenberg, P. P., Frijters, D. H., Ribbe, M. W., & Groenewegen, P. P. (2011). Communication, advice exchange and job

satisfaction of nursing staff: A social network analyses of 35 long-term care units. *BMC Health Services Research*, 11(1), 140.

van der Doef, M., & Maes, S. (1999). The Leiden Quality of Work Questionnaire: Its construction, factor structure, and psychometric qualities. *Psychological Reports*, 85(3), 954-962.

van Saane, N., Sluiter, J. K., Verbeek, J. H. A. M., & Frings-Dresen, M. H. W. (2003). Reliability and validity of instruments measuring job satisfaction: A systematic review. *Occupational Medicine*, 53(3), 191-200.

Vernooij-Dasssen, M. J., Faber, M. J., Olde Rikkert, M. G., Koopmans, R. T., van Achterberg, T., Braat, D. D. *et al.* (2009). Dementia care and labour market: The role of job satisfaction. *Aging and Mental Health*, 13(3), 383-390.

*Wallin, A. O., Jakobsson, U., & Edberg, A. K. (2012). Job satisfaction and associated variables among nurse assistants working in residential care. *International Psychogeriatrics*, 24(12), 1904-1918.

Wallin, A. O., Edberg, A. K., Beck, I., & Jakobsson, U. (2013). Psychometric properties concerning four instruments measuring job satisfaction, strain, and stress of conscience in a residential care context. *Archives of Gerontology and Geriatrics*, 57(2), 162-171.

*Willemse, B. M., de Jonge, J., Smit, D., Depla, M. F., & Pot, A. M. (2012). The moderating role of decision authority and coworker-and supervisor support on the impact of job demands in nursing homes: A cross-sectional study. *International Journal of Nursing Studies*, 49(7), 822-833.

*Willemse, B. M., De Jonge, J., Smit, D., Visser, Q., Depla, M. F., & Pot, A. M. (2015). Staff's person-centredness in dementia care in relation to job characteristics and job-related well-being: A cross-sectional survey in nursing homes. *Journal of Advanced Nursing*, 71(2), 404-416.

World Health Organization. (2012). *Dementia: A public health priority*. World Health Organization. Geneva: WHO Press. Retrieved 18th October 2015 from www.who.int/mental_health/publications/dementia_report_2012/en/

*Zimmerman, S., Williams, C. S., Reed, P. S., Boustani, M., Preisser, J. S., Heck, E. *et al.* (2005). Attitudes, stress, and satisfaction of staff who care for residents with dementia. *The Gerontologist*, 45(suppl 1), 96-105.

* denotes the 11 papers chosen for the main review

Part two: Research report

'Inappropriate Sexual Behaviour in dementia: The lived experience of caregivers'

Abstract

Background

Inappropriate Sexual Behaviour (ISB) can be distressing for those who experience it. Despite its negative impact, little attention has been devoted to examining ISB in dementia, particularly how it is experienced by informal caregivers. This study aimed to explore the experiences of family caregivers living with and caring for someone with dementia who displays ISB.

Method

Potential participants were invited to take part in the research through a number of dementia and older adult services. Interpretative Phenomenological Analysis was used to explore the lived experience of two caregivers (Anne and Michael) caring for a spouse with dementia who exhibits ISB.

Results

Analysis illustrated two different narratives. On a daily basis Anne experienced unrelenting ISB directed at her which was aggressive at times. Michael did not interpret disrobing behaviour displayed by his wife as ISB, but attempted to cope with other people's view that it was ISB. Tentative analysis across both cases revealed some convergence. Both caregivers used psychological defences such as distancing to cope with the behaviour and attributed ISB to dementia. ISB also compounded the loss of their respective partners' self-identity and shrunken social circles which arose from the onset of dementia. Furthermore, the caregivers experienced stigma associated with dementia which was exacerbated by ISB.

Conclusion

This study provides a unique insight into the distress caused by ISB for informal caregivers. It highlights the importance of continuing to raise awareness of such behaviour with a view to reduce the stigma associated with it and improve support.

1. Introduction

1.1 Background

There are currently approximately 850,000 people living with a diagnosis of dementia in the UK, with this number potentially increasing to over two million by 2051 (Alzheimer's Society, 2014). These degenerative conditions are recognised to confer significant burden, both to those delivering health care and those in informal caring roles, often family carers. The National Dementia Strategy described family caregivers - those who provide unpaid support to family or friends who could not manage without such help (Princess Royal Trust for Carers, 2014) - as the most important resource for a person with Dementia (DoH, 2009).

In the UK there are over 670,000 people caring for a relative or friend with dementia (Alzheimer's Society, 2014). For informal caregivers, taking on the responsibility of caring for a loved one can be a rewarding, but stressful role (Heru *et al.* 2004), implying significant changes in one's own life. It may mean facing a life of financial difficulty, isolation, frustration, ill health and depression, and many caregivers relinquish income and future employment prospects (Chang & Horrocks, 2006; Joling *et al.* 2010; Papastavrou *et al.* 2007; Pinquart & Sorensen, 2006; Princess Royal Trust for Carers, 2014; Sanders *et al.* 2008; Takai *et al.* 2009). Given the importance of caregivers, their wellbeing ought to be prioritised. Indeed, this appears to be acknowledged in research literature given an abundance of studies examining the impact of caring, and strategies to ameliorate any adverse effects (Brodaty *et al.* 2003; Chien *et al.* 2011; Corbett *et al.* 2012; Schoenmakers *et al.* 2010; Selwood *et al.* 2007; Zarit & Femia, 2008).

Caregiver wellbeing can be adversely affected by a number of factors such as the emotional impact of grieving the loss associated with dementia (Aminzadeh *et al.* 2007; Robinson *et al.* 2005). A prominent factor is the behaviour of those with dementia – notably behaviour which is perceived as challenging; physical and verbal aggression, inappropriate sexual behaviour (ISB), disturbed sleep patterns and wandering (Bird, 1999). The negative impact of challenging behaviour both for formal and informal caregivers is well documented in the literature in terms of burden, emotional exhaustion, fear of safety and physical

injury (Gaugler *et al.* 2005; Kristiansen *et al.* 2006; Papastavrou *et al.* 2007; Scott *et al.* 2011).

Inappropriate sexual behaviour

Despite an extensive literature on challenging behaviour, less research attention has been devoted to exploring the impact of ISB (Alagiakrishnan *et al.* 2005; Johnson *et al.* 2006; Knight *et al.* 2008). Whilst it has received relatively little research scrutiny, its impact on caregivers and staff may be just as significant as other forms of challenging behaviour, since it can be embarrassing, disruptive, impair the care of the patient, and engender distress in staff who are exposed to it (Alagiakrishnan *et al.* 2005; Black *et al.* 2005; Onishi *et al.* 2006; Robinson, 2003). Research measuring the prevalence of ISB exhibited by people with a dementia varies between 1.8% and 17.5% (Ward & Manchip, 2013), however due to limited research on ISB this may be an underestimation.

ISB is defined differently throughout the literature and a number of classifications of the behaviour exist. In their review of the literature Johnson *et al.* (2006) identified a number of terms used to describe the behaviour including 'hypersexuality' and 'sexual advances'. The authors advanced the definition as 'a verbal or physical act of an explicit, or perceived, sexual nature, which is unacceptable within the social context in which it is carried out' (Johnson *et al.*, 2006, p. 688). The subtle nature and subjectivity attached to ISB (it may demonstrate needs that are not necessarily sexual) can impede clarity. Tsatali *et al.* (2011) noted sexual behaviour may both demonstrate a patient's needs to feel close to another person and a legitimate wish to sexual expression which can be misconstrued by staff as challenging behaviour.

There have been various systematic attempts to categorise ISB such as the St Andrew's Sexual Behaviour Assessment (SASBA), a validated tool that can be used to measure the behaviour (Knight *et al.* 2008). The SASBA classifies four types of ISB: verbal comments (including explicit accounts of sexual intent), non-contact behaviour (including masturbating in public settings), exposure (including exposing genitals) and touching others (including touching another person's genitals). This tool allows healthcare professionals to objectively record the frequency and severity of ISB.

Even though it is recognised that ISB can have a negative impact on carers, professionals and the individual displaying the behaviour, there exists a very circumscribed literature conducted within forensic and traumatic brain injury populations (Hayward *et al.* 2012). This may reflect the aforementioned inconsistencies in conceptual and operational definitions of the term, as well as attitudes towards sexuality in later life, too often misunderstood and stigmatised. Sexual expression in older adults has long been taboo (Gott & Hinchliff, 2003), with older adults themselves prone to self-censor sexual expression in the context of illness and widowhood. A review by Benbow and Beeston, (2012) also suggested that negative beliefs and attitudes towards sexuality in older age are shaped by stereotypes, myths and messages from the media. The negative impact of these views on sexuality in later life is such that an older person with dementia who is trying to express their needs or seek closeness from another person may be labelled as displaying ISB.

Here-in lies a conflict between the importance of recognising the sexual needs of older adults, but also protecting caregivers and health care professionals who may be the unwelcome recipients of such expressions. As noted earlier, sexual behaviour may be deemed inappropriate dependant on the context in which it is displayed. Hayward *et al.* (2012) explored the experiences of in-patient staff members of ISB as exhibited by older adults with dementia. The study demonstrated the way ISB may be construed and how this interpretation can be affected by individual values. In terms of putting ISB into context certain aspects such as individual values, patient familiarity and social norms were all important. Furthermore, the authors suggested that the impact of ISB should be routinely considered when preparing staff to work in dementia care (Hayward *et al.* 2012).

ISB and familial caregiving

Research to date on ISB presenting in those with dementia has largely emerged from residential homes or inpatient settings with very little attention given to informal caregivers at home (Hayward *et al.* 2012; Stubbs, 2011). As noted previously, challenging behaviour and ISB would exemplify this significant and adverse impact on the life of a familial caregiver. Recognising such impact, Alagiakrishnan *et al.* (2005) suggested that health professionals who are involved

in the care of patients with dementia should receive regular training to prepare them to handle ISB, whilst Stubbs (2011) advocated clinical supervision as a useful tool for nursing staff to discuss their experiences of ISB. However, in the community, caregivers may not have access to similar training and support. Robinson, (2003) described how the perceived embarrassment of ISB could increase the social isolation of a family caregiver and explained that they may also fear this behaviour will be directed at visiting healthcare professionals. This further demonstrates the potential impact of ISB on the life of a caregiver; not only may it limit their own social contacts and opportunities for respite, but it may also prevent them seeking the support they need.

It is necessary to try and understand the experiences of caregivers who are exposed to ISB; in dementia care there are always two clients, the patient and the caregiver (Yap *et al.* 2005). Very few studies have adopted a qualitative approach to sexually related issues with older people (Gott & Hinchliff, 2003) and to the current author's knowledge no studies have explored in depth the caregivers lived experience of ISB when caring for someone with dementia. Research that has focused on the experience of other aspects in caregiving has highlighted the benefits of taking this approach. In their study, Chan *et al.* (2010) noted that understanding the caregiver experience is important with regards to the design of support services and can highlight sources of strain and unmet needs. Whilst De Casterle *et al.* (2011) suggest that if the understanding of a situation as lived by those involved is clearer, it will help to decide what informs good care in specific situations, in this case ISB.

Given the essential role of the caregiver, the potential negative impact of ISB on their life, and the paucity of research that has explored this topic it is relevant to address this issue. It is necessary that this neglected behaviour is understood from the perspective of the caregiver, especially so in a world with broadening, but still limited attitudes towards sexuality (Bouman *et al.* 2006). Research incorporating the lived experience of caregivers with a focus on ISB may help illuminate the unique elements of this phenomenon and add new direction to the substantial literature that exists for other forms of challenging behaviour in dementia care.

1.2 Aim

The aim of this study is to describe and construct an interpretation of the lived experiences of informal caregivers who experience behaviour that could be described as ISB. This will enhance understanding of the caregivers' perceptions of ISB and how it impacts on their life. Understanding individual interpretations of ISB and the associated stigma may also allow caregivers to better communicate these difficulties and healthcare professionals to more confidently address them. To this end the research aims to explore the following question: What are the experiences of informal caregivers caring for someone with dementia who displays ISB?

2. Methodology

2.1 Study design

A qualitative design which utilised an Interpretative Phenomenological Analysis (IPA) approach was selected for this study. IPA is appropriate for research in areas with limited exploration (Reid *et al.* 2005), and there have been no studies to date devoted to understanding the lived experiences of ISB in the process of caregiving. IPA is an idiographic approach that will give caregivers a voice (Larkin *et al.* 2006) providing the opportunity to gain an in depth understanding of how they make sense of their own personal experiences of ISB. As the topic of the research is considered to be sensitive, recruiting a high number of participants willing to discuss ISB may potentially be difficult; IPA allows one to carry out in depth analysis on a small number of participants (Smith *et al.* 2009).

2.2 Researcher context

Reflexivity is imperative as IPA involves a dual interpretation process or 'double hermeneutic' in that the researcher is attempting to make sense of the participants making sense of their world (Smith & Osborn, 2003). It is important that the researcher is aware of what they are bringing to the interpretation. The researcher's context and epistemological position of a critical realist are detailed in Appendix F and G respectively.

2.3 Participants

As the aim of IPA is to develop a detailed account of individual experience, studies using this approach tend to be focused on a small number of cases (Smith, 2004). Smith *et al.* (2009) recommend between three and six participants

as an approximate; the aim was to recruit up to six participants for the current study.

The criteria for inclusion in the study was individuals who were the spouse and primary caregiver of someone who had a diagnosis of dementia and had experienced behaviour that could be considered sexually inappropriate. As the use of IPA calls for a degree of homogeneity in the sample (Smith *et al.* 2009) only spousal caregivers were invited to take part in the research to account for possible differences in the way different types of relatives (such as adult-children compared to spouses) experience ISB; for example, adult-children may feel uncomfortable thinking of their parent within a sexual context (Bauer *et al.* 2014). Furthermore, spouses are the predominant care providers for individuals with dementia (Baikie, 2002; Braun *et al.*, 2009). The primary caregiver was defined as an individual living with someone who has dementia and the main person providing care. Additionally, caregivers had to be over the age of 18, informal, and able to understand and speak English to a level capable to complete the interview. Potential participants were excluded if they were not living with the person they cared for or the care recipients did not have a diagnosis of dementia.

Initially recruitment took place through two services: A Young Person Dementia (YPD) team and a carer support service (CS). The YPD is a community based service designed for people under 65 years who have a diagnosis of dementia. The CS is an independent charity which offers support to carers. Due to recruitment difficulties², the researcher was later permitted to recruit through four Older People Community Mental Health Teams (OP-CMHT) and Join Dementia Research (JDR) – an online research recruitment service.

Two participants (Table 1) were recruited for the project, both identified through the CS. Nine further caregivers were identified, six did not take part for a number of reasons including managing other stressors, family members being in hospital and not being able to have time away from the care recipient. Three caregivers did not give reasons. Despite having two participants IPA is an approach that can be adopted even in the instance of one case (Larkin & Thompson, 2012) and

² The difficulties in recruitment are further discussed in the critical appraisal section of this report.

conducting an IPA analysis is more problematic with a sample size that is too big rather than too small (Smith *et al.* 2009).

Table 1: Participant demographics.

	Participant 1 (Anne)	Participant 2 (Michael)
Gender	Female	Male
Age range	60-69	60-69
Relationship to care recipient	Wife	Husband
Employment status	Self-employed (part-time)	Retired
Ethnicity	White British	White British
Number of years caregiving	3	5

2.4 Procedure

2.4.1 – Ethical approval and considerations

Ethical approval was granted by the National Research Ethics Service Committee East Midlands. Minor amendments were also approved in November 2015 and February 2016, these letters can be seen in Appendix H.

Anonymity and confidentiality were maintained by ensuring that only the researcher knew the names of the participants; pseudonyms were used in the transcriptions and results. Participants signed a consent form before participating in the interview. As there was a possibility of distress being evoked, participants were informed that breaks could be asked for during interviews. Further to this, they were offered the opportunity to discuss any feelings of distress after the interview. The audio recordings and electronic transcripts were kept on a password protected computer which only the researcher had access to.

2.4.2 – Data collection

The use of one-to-one semi-structured interviews were utilised for data collection. In reviewing the literature on challenging behaviour and ISB in dementia, draft questions were developed on broad themes. The topic guide (Appendix I) was

discussed with the research supervisors and two individuals who had experience of caring for somebody with dementia. Both caregivers provided feedback that whilst the interview may evoke some distress, the questions were important to gain the most relevant information.

Potential participants were identified and invited to participate by members of staff from each of the services involved in the study. They were given a participant information sheet (Appendix J) for the study, an 'opt in' form (Appendix K) and a stamped addressed envelope to return the 'opt in' form to the researcher. The researcher contacted participants once he had received a completed 'opt in' form.

The location of interview was determined by the participant's preference; one interview took place at a participant's home and one took place at a community clinic. Each participant signed a consent form (Appendix L) before the interview was conducted. Following the interview with participant one, the researcher identified a risk concern³ which he discussed with the study supervisors. He arranged a meeting with the participant to discuss his concerns and was informed that the risk issue had been resolved. Furthermore, the participant had previously given consent to a second interview; this was a beneficial opportunity as the aim of IPA is to explore participants' experiences in depth and valuable given the difficulties in recruiting participants. Each interview was audio recorded and transcribed verbatim by the researcher based on suggestions by Smith *et al.* (2009). As the aim of IPA is to analyse content, it should detail all words spoken by those present in the interview; it does not require detailed transcription of the prosodic aspects of the recording such as the exact length of pauses (Smith *et al.* 2009).

2.5 Analysis

The analysis of the results was guided by the process described by Smith *et al.* (2009). Given that IPA adopts an idiographic stance each transcript was analysed individually in detail before the next was examined. Transcripts were initially read and re-read to facilitate familiarisation with the participants and their experiences. Following this, coding was used to develop an intimate engagement with the data through noting of initial comments. The researcher stayed close to the

³ The risk related issue is further discussed in the critical appraisal section of this report.

participants' explicit meanings and identified things which seemed important to the individual.

After this stage, the coding was transformed into emerging themes by looking for patterns and connections between initial notes. This involved frequent shifting between inductive and deductive positions as the researcher attempted to stay close to the participants accounts whilst developing their own understanding of the described phenomenon. An example of a transcript section which consists of initial comments in the left hand column and emerging themes in the right hand column can be seen in Appendix M. The next stage of the analysis involved drawing together emergent themes by looking for connections and grouping them together. Each theme was written on separate pieces of paper; the researcher was then able to move themes around pulling them together in clusters. Each cluster was given a name in order to conceptualise the themes within them.

It is important to capture the individual essence of each participant, to an extent 'bracketing' off the emerging ideas from the previous case (Smith *et al.* 2009). The researcher attempted to remain open to the emergence of new and different themes in each case by staying as close as possible to each individual account. Following individual analysis, an exploration of themes across all participants was conducted looking for convergent and divergent patterns in the data. The analysis of each participants' data resulted in themes that fitted into three superordinate themes: 'what the behaviour means to me'; 'the change in our relationship'; and 'making sense of outsiders'. Even with just two participants, the super-ordinate themes conveyed both convergence and divergence in the experiences of caring for a spouse who displays ISB; a super-ordinate theme may vary in how it is evidenced across cases as participants may share the theme through different sub-themes (Smith *et al.* 2009). An example of how a selection of transcript text and initial emerging themes contributed to a superordinate theme can be seen in Appendix N.

2.5.1 – Methodological rigour

Various strategies were applied throughout the research process to ensure and maintain quality of analysis; further details are provided in Appendix O.

3. Results

The sub-themes are presented under each of the three superordinate themes and accompanied by direct quotes⁴. Figure 1 below illustrates a diagrammatical representation of the three super-ordinate-themes and the sub-themes within these.

What the behaviour means to me

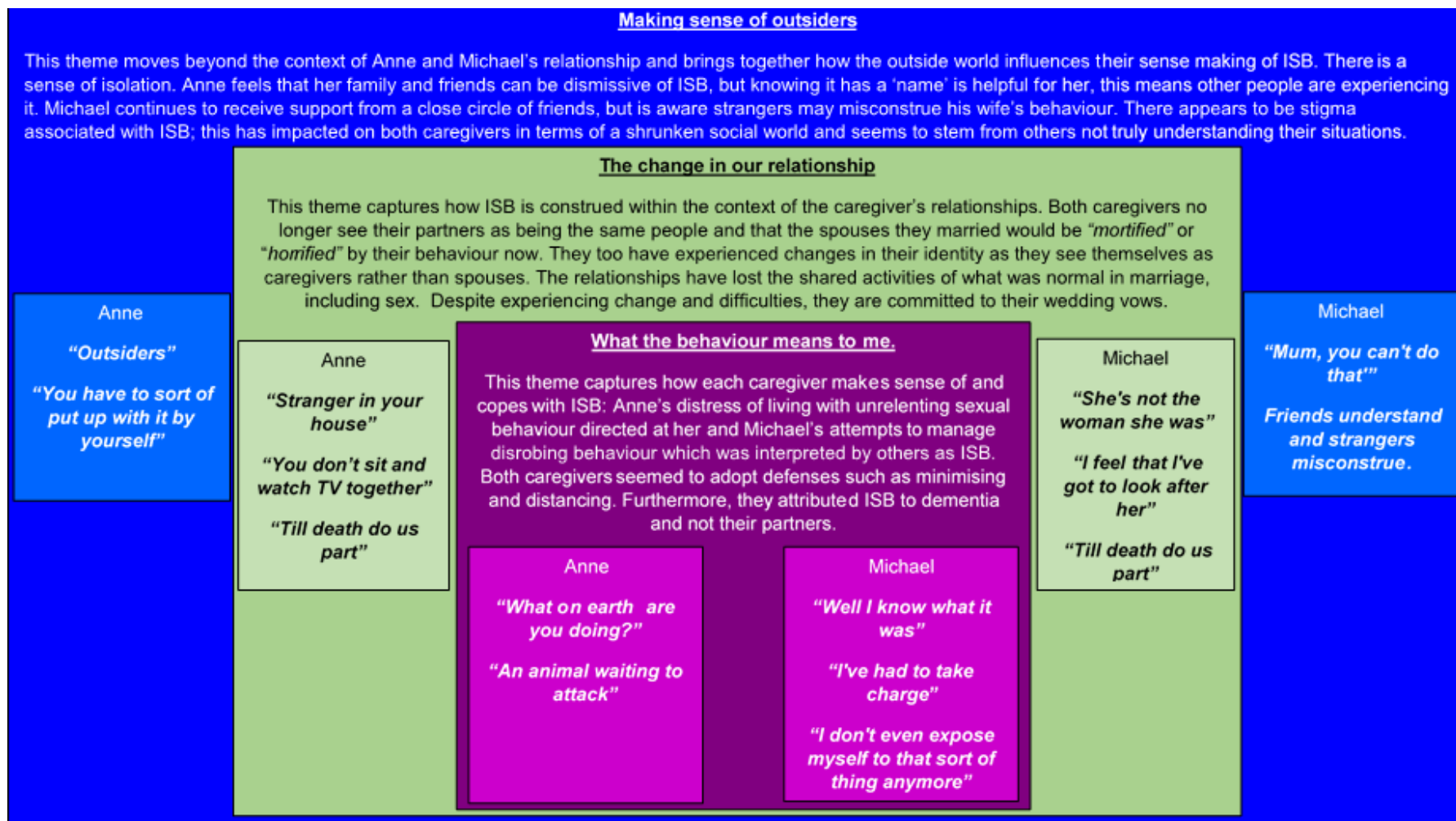
This first superordinate theme encompasses the sense-making of Anne and Michael regarding ISB and its impact on their lives. In contrast to the other superordinate themes, there is mainly divergence between the two participant's here, with relatively little convergence. This is partly due to the nature of the ISB being very different in each case. Anne's husband (John) was behaving in a clearly sexual manner towards her that mostly occurred within the home, unseen by other people. On the other hand, Michael's wife's (Julie) ISB involved taking her clothes off; this presented as more ambiguous in motive, and occurred in public as well as private.

Anne understood her husband's behaviour as sexual and predatory. Michael on the other hand did not consider his wife's behaviour as sexual in any way. He was included in the study despite this, as her undressing behaviour is included in definitions of ISB (Knight *et al.* 2008; Ward & Manchip, 2013), and could be construed as sexual by others, making Michael's rejection of a sexual interpretation of interest.

Michael persistently gave non-sexual interpretations of Julie's behaviour, particularly one that she wanted to go to the toilet and that was why she removed clothes. Whilst sometimes this could be a plausible interpretation, at other times it could be interpreted as denial. Denial of a sexual interpretation spares him from having to deal with difficult feelings that may arise such as shame and embarrassment. Anne also seems to have a strategy for coping with the difficult feelings arising from the fear that John could attack her by ascribing it to the

⁴ Quotes include line numbers to facilitate location within transcripts. Anne's quotes also detail which of her interviews they were taken from. (.) represent pauses in speech. Interjections and non-verbal expressions are written in brackets. Text omitted from a quote is denoted by... and interviewer speech is written in bold.

Figure 1: Thematic diagram



illness, and him being out of control: *“he can’t help it”*. She had to deal with the fear of being hurt, but could spare herself the feeling that would arise from blaming John rather than the illness.

Overall, while the details of the nature of ISB are different, both appear to use defenses such as denial, minimising, distancing and avoidance to manage difficult feelings as evidenced in the following sub-themes.

“What on earth are you doing?”⁵

Anne initially struggled to grasp why John was displaying ISB; repeating *“I don’t know”*. She settled on an explanation that it is due to his illness and hence out of his control:

...but that’s part of his illness I think. I presume(.) So I don’t know, I don’t know whether it is the Alzheimer’s or the dementia, whatever he’s got, I don’t know.

Interview 1: 144-146

... All I, all I keep thinking- -all I keep saying is he can’t help it. He can’t help it.

Interview 1: 362-363

Anne repeats *“he can’t help it”*, perhaps to convince herself that it was not deliberate. The diagnosis of dementia served to distance John from responsibility; further highlighted by Anne in her second interview.

...if somebody is normal and they make these remarks or movements you can tell them to clear off can’t you and when someone has got dementia you can’t...

Interview 2: 47-49

Her use of third person suggests a need to psychologically distance John from these behaviours. Attributing ISB to the illness rather than John also distances him from the responsibility. While this may be helpful in de-personalising the cause of ISB, Anne continued to find it difficult to rebuff him as there was no longer love behind John’s intentions:

... Because he doesn’t, he never talks to me lovingly because he’s got this aggression and he can be really awful and call me an ‘effing evil bitch and then

⁵ Theme names in quotation marks represent an in vivo code.

five minutes later(.)he's erm(.)he wants to touch me and things.

Interview 1: 352-355

Anne's description of being called an "*effing evil bitch*" sharply conveys how aggression has replaced affection. As she struggled with the loss of love she also had to contend with a behaviour which now frightens her.

"An animal waiting to attack"

This sub-theme reflects the enduring trepidation for Anne living day to day with ISB directed at her. Anne underlined the intrusiveness and relentlessness of the behaviour when she said:

... little remarks he makes as well, everyday there's remarks about sex, everyday(.)erm(.)right up until bedtime... not, er(.)an hour goes by in the day when he don't(.)mention sex, or(.)he just touches me when he goes by...he stands in front of me and takes his trousers and his underpants down, while I'm on the phone...

Interview 1: 42-49

So every time I'm having a shower and I look up and he's standing behind the other side of the glass(.)looking in at me.

Interview 1: 21-22

Even when John wasn't around, she had to remain alert in anticipation of what may happen.

...I'm glad if he went off to bed, so I get a bit of peace. But then- -but now, it's it's- -he is like waiting for me. It's like erm(.)it's like an animal waiting to attack...

Interview 1: 430-432

The metaphor "*an animal waiting to attack*" portrays a powerful image of a predator stalking prey. Anne feared for her safety:

...I worry sometimes that he might(.)I wouldn't say rape me, but force me. I often wonder if it will come to that, because it never leaves his mind.

Interview 1: 186-188

The words "*rape*" and "*force*" suggest feelings of powerlessness to stop him if he were to "*attack*". Anne was also in the 'animalistic' hyper-vigilant survival mode,

saying that she could “sense it” if John was watching her. During the second interview Anne explained that following the prescription of new medication John’s aggression and ISB had stopped:

I'd rather put up with the way he is now, erm(.)just a bit agitated, but no, no sexual thoughts what so ever. I'd rather put up with how he is now than I did how he were before when he got all thus funny behaviour, 'cos I felt quite threatened then...

Interview 2: 698-701

Anne continues to experience challenging behaviours from John, but they are non-threatening. She repeats three times in this extract that she would rather he be as he is now, emphasising that it was an experience she never wants to go through again.

“Well I knew what it was”

In stark contrast to Anne’s struggle with making sense of John’s behaviour, Michael asserts simple, non-sexual explanations for his wife’s disrobing. Michael does not associate sexuality with older people such as them, so he found other explanations:

You might well view it as sex- ... I mean if you've got an old lady come in there and start doing it you wouldn't obviously...the younger people get dementia, the more inappropriate that's going to look, isn't it. Erm, but I mean if you've got somebody in their seventies do it, you're not really going to think that way, you are going to think, 'oh, she's got a problem'.

343-350

... it never bothered me really because erm, you know I knew what was happening...it was obvious what was going on to me, so I never really had any sort of other feeling than trying to get her to the toilet or out of the way or something like that.

117-121

Michael repeatedly uses the explanation of needing the toilet when Julie removes her trousers, however, he is less sure of the reasons for taking her top off in public and suggests three possible reasons for the behaviour:

Erm, I just think that was, that was just a erm(.)just(.)like a childlike sort of feeling. She probably got hot or something and just decided to take her top off or erm, just a lack of inhibitions really of where she was or situations.

97-100

He attributes it to either a childlike feeling, just getting hot or a lack of inhibitions. His repeated use of the word “just” has a minimising quality as he is suggesting it is one of these reasons, nothing sexual. This interpretation may spare him from embarrassment that a sexual motive may elicit.

“I’ve had to take charge”

This sub-theme reflects Michael’s view of the behaviour as manageable, therefore it is not a problem to him. Disrobing for him is merely one of many challenging behaviours that Julie displays, and one he feels able to control:

...I’m saying that’s just part of the problems that I’ve had to have all along, like erm, like the hallucinations, you know. Erm, like all the problems that I’ve had, erm, with her, it’s just one of many that you just- -oh it’s just something else that’s happening. Erm, yeah, that’s just something else that- -it’s just one of a long line of different problems...

784-789

...to my mind this erm business of going- -taking her trousers down [laughs] if you like, is, just a part of the behaviour pattern and it’s you know, it’s something that triggers me to know what, what her problems are, erm, it’s just something that happens and that’s it, you know.

276-280

As before, Michaels repeated use of the word “just” suggests an attempt to minimise the behaviour. If it is being reduced to “just something that happens” it suggests something manageable.

There is a sense that the numerous behavioural difficulties could feel overwhelming as he talks about a “long line of different problems”. Minimising these behaviours may be a way of coping. This is further reflected when he says:

...I've had to take charge of all these little problems that have come with dementia, which have manifested...nobody's been there to help, and so I've had to take on board all these little problems- -part of the whole clothes off business has just been part of a huge great wedge of problems, you know.

834-840

Yeah, it's, it's just a minor- -something that happens and you just take it in your stride with all the rest of the problems.

188-189

There is an accumulation of problems, but resilience is maintained as long as the disrobing behaviour remains a small part of the bigger picture.

“I don't even expose myself to that sort of thing anymore”

This sub-theme explores how Michael may be avoiding difficult feelings around coping with Anne's disrobing. Some of her behaviour may well be about going to the toilet, or that the disrobing is actually just a small element of a constellation of challenges faced by Michael. It is also possible that there are defensive strategies such as minimising, denial and avoidance occurring. This sub-theme captures moments in Michael's account when it seemed there was more to the disrobing behaviour than it being just a little problem.

Initially in the interview Michael explained that Julie disrobing is not embarrassing.

...it really doesn't bother me whether anybody thought it was sexual or not, if you know what I mean.

Can you tell me a bit more about that?

... I knew- -know she wouldn't do anything you know like, like that- -to embarrass me as such. It's, so it's erm(.)it's not an embarrassment to me, it's just something that I've got to deal with...

160-170

His reasoning for not being embarrassed by the behaviour is that Julie would not intend to embarrass him. This suggests that it is the intention behind Julie's

behaviour that could potentially embarrass him, not how others would view it. Later in the interview he does acknowledge that it could be embarrassing. Michael also suggests that others could sympathise with his situation, an acknowledgement that it is difficult.

...when your wife has exposed herself, have you noticed how other people react in the community?

... I suppose I haven't, haven't really because, not(.)I haven't gone round and asked their initial reaction, because they obviously erm, eh, are embarrassed for her aren't they, you know what I mean, and probably feel sorry for me...

557-563

Although Julie disrobing in public could be a potentially embarrassing situation, Michael says he is not embarrassed, perhaps because he does not care what others think. He may be able to contain any embarrassment as long as he is secure in knowing his wife does not intend to embarrass him. It could also be that he avoids putting himself in situations where he could get embarrassed.

...we don't get into the social circles now that, that we, that we did, you know, we never erm- -I mean we used to go to like concerts and things, we can't do that now. I think you restrict everything that you do erm, whereas if she probably did stuff like that in, in, in social areas, yeah it probably would be a bit embarrassing, but we don't- -I don't even expose myself to that sort of thing anymore, so erm, you know it doesn't arise.

417-423

Interestingly he uses the word “expose”. Is he communicating that he too feels exposed when Julie exposes herself? Hence he now avoids social areas. Whilst Julie disrobing in public may not be the only reason Michael restricts their social circle, the potential embarrassment could prompt a need for him to avoid it.

The change in our relationship

This super-ordinate theme moves from the focus of ISB and its impact on carers, to how they experience their personal relationships. For both Anne and Michael

there are profound changes in their spouses making them “a stranger” or “not the woman she was”. They note that the spouses they married would be “mortified” or “horrificed” by their behaviour now. Anne and Michael have also had changes to their identities within their relationships, e.g., Anne feels no longer treated as ‘wife’, reduced to ‘an object’ and like Michael has become a ‘carer’ rather than a ‘husband’. The relationships have lost the shared activities of what was normal in marriage, including sex. However, both participants feel bound by the marriage vows, and cite “till death do us part”.

“Stranger in your house”

This sub-theme depicts Anne’s view that John is no longer the same person and likens the changes in him to having a “stranger in your house”:

Because John was different, 'cos his- -he became not him with this dementia, he- -it(.)well he's never been the same since...

Interview 2: 72-73

Anne explains that John would be “absolutely horrified” if knew he was displaying ISB. This illustrates the contrast between the man she married and who she lives with now. Viewing him as a stranger may make it easier for Anne to acknowledge the behaviour rather than if it was being displayed by the John she married. In the extract below Anne used the words “their” and “them” as opposed to ‘him’, perhaps further distancing John from ISB.

...it's not your husband whose saying these things and doing these things, it's like as if another person's took over their(.)them...

Interview 2: 479-481

Anne see herself as a stranger as well as John. She does not know who she is anymore whether it be wife or carer, and at times feels reduced to a sexual object.

When he's like- -he don't know the day or the time or where he is gonna' go that day. He always asks this question “where am I going to go today”. I'm like the carer whose telling him the time, sorting his clothes out...

Interview 1: 646-649

... I wasn't treated like a wife should have been, I was just treated like a sexual object...

Interview 2: 665-667

Anne is struggling to hold onto her identity as wife. She is reduced to “*object*” and “*carer*”. Despite being “*strangers*” their lives remain intertwined. For Anne her life has “*ended in a way*”, she does not have her own life separate from John as her “*main concern is, is looking after him*”. The following extract gives a sense of Anne not having space for her own needs and the word “*smothering*” reflects the idea of being suffocated or trapped with no way out; in a sense her life coming to a metaphorical end.

...we all need our private times where(.)you know, having a shower, having a wash or doing things like that. It's your space and it is- -he keeps getting into my space. It's as if he is erm smothering me.

Interview 1: 283-286

“She's not the woman she was”

Like Anne in the last sub-theme, Michael has had to deal with changes in Julie as a person. In particular, it has meant that he is no longer sexually attracted to her.

Michael and Julie have known each other a long time and because of this he sees aspects of her personality that are completely different. The disrobing behaviour demonstrates how much she has changed.

How do you think Julie would feel about the, the- -her taking her clothes off in public?

She would be mortified, she would be absolutely mortified, you know. In her younger self she would have- -it wouldn't have even entered into her head to do anything like that, you know. Erm, she, she was a very if you like, modest person. Erm, but her whole personality has changed...

798-805

Michael emphasises that Julie would be “*mortified*” about disrobing in public, conveying a vast change in her. Her whole personality has changed, leaving little

sense of her as his wife. He is no longer attracted to Julie and on numerous occasions commented upon her personal hygiene.

... she has just grown unattractive and yet I still feel obviously a need to look after her ... it's not just a case of- -it's not just a case of her smelling, I have to sort of worry- -she wets the bed, she makes messes in the toilet ... So that whole aspect of it has turned me off her, sexually, if you know what I mean.

920-926

Michael said “*she’s not the woman she was*”. He no longer sees his wife Julie, but a woman who disrobes in public, has poor personal hygiene and needs support. He seems to be viewing her from the caregiver role he has adopted, possibly distancing his wife from the woman he lives with now; his wife would not behave like this, she would be “*mortified*”. In the extract above Michael explains that he no longer has any sexual feelings towards her. However, it is not just the change in Julie, Michael also attributes his own reduced sexuality to not being attracted to her in this way.

... I guess I've got older and you know more erm- -or less sexually active I guess, you know. I think that's the easiest way of putting it really. Erm, I, I suppose- -and I don't really know about erm, what happens- - what ages guys lose the ability to be sexually attract- -obviously erm, it's great to see these girls sort of take their clothes off, erm, but you don't view it in the same way that you did- -that I did 20 years ago and I think that is probably what it, what, what it's all about really.

400-407

The disrobing behaviour may have sexually excited him when he was younger, but not now; they have both become de-sexualised.

“You don’t sit and watch TV together”

This sub-theme reflects Anne’s loss of all that is normal in their relationship:

...erm(.)well when you don't have any fun and you can't discuss, you, you don't sit and watch TV together, you don't really enjoy a meal together(.)the relationship's entirely different.

Interview 2: 517-519

“You don’t sit and watch TV together” is poignant as it suggests that their relationship has changed to the point that they cannot enjoy such a simple act:

A normal life(.)I don’t ask for anything, I’d just like- -if- -like if John was okay(.)he’d potter about and do what he does and I’d do my bits, we would have a nice meal together, we would probably go to the cinema or for a meal, laugh at a joke. All the things I haven’t got now, that’s what I call normal.

Interview 2: 610-614

Anne has lost all that was normal for them. With regards to sexual behaviour she described how a sexual relationship is normal for a married couple.

... well when your husband and wife, you are supposed to participate in all of these things, and it’s as if I’m refusing him or avoiding, which I am.

Interview 1: 420-422

It is not only that she is “supposed” to, but Anne still wants to engage in a sexual relationship, but is put off by his ISB.

Erm, I did try and explain to him, “if you don’t keep talking about it, you, you have to let things like be natural, there’s feelings there, things will happen”. But he can’t grasp that what he’s doing is, is actually(.)putting me off him(.)a lot. Then you feel guilty because you are his wife.

Interview 1: 411-415

Anne feels guilty for not engaging John sexually because she is “his wife” and that is ‘normal’ behaviour within a marriage. That John wanted to act on sexual behaviour did not seem to be a problem, it was the way he displayed it which was not acceptable.

... I don’t like it, erm, ‘cos he’s not looking at me as is wife, he’s looking at me as(.)who he can say anything to sexually and thinks he’s got the right to(.)as I say walk in the bathroom and watch me having a shower, and, or touch me as I walk by and I don’t think he’s got that right(.)not just ‘cos he’s married to me...

Interview 1: 1097-1102

Anne strongly conveyed that ISB is not condonable even if you are “man and wife”. Anne views sexual behaviour as permissible if there is mutual consent. The

sexual behaviour displayed by John is inappropriate as it is one sided and at times forceful, as described in the sub-theme “An animal waiting to attack”.

‘I feel that I’ve got to look after her’

This sub-theme conveys the transition for Michael from husband to caregiver and Julie from wife to care recipient. He reflects on his experiences of caring for his Mother who also had dementia and how this shapes some of his thoughts and feelings towards Julie.

Julie has become dependent on Michael to the point where he thinks about what would happen if he wasn’t around to support her.

... she doesn't wash, she doesn't wash, -she doesn't do- -you know she doesn't change her clothes unless she's really prompted. Erm, we've even got the problem now, she, she erm, occasionally wets herself...

324-327

... if I wasn't with her, she would just take her clothes off and go, if you know what I mean [laughs], and that could be construed as all sort of problems, couldn't it really, you know.

141-144

This relates to the “*I’ve had to take charge*” theme in the sense that the potential for Julie’s behaviour to escalate is controlled by Michael adopting a caregiver role. If he did not take charge her hygiene would deteriorate or she might disrobe in public. Michael draws on his experience of caring for his Mother who also had dementia; he became the carer rather than being her son. The following extract conveys a parallel in his feelings towards Julie.

...she's replaced my Mother, you know, I'm getting the same feelings for her as when I had to look after my Mum, and erm, and now I feel I'm feeling I have to look after her as something that happened...

728-731

The word “*replaced*” suggests that Michael feels like he is going through the same experience again, with a change in roles from son or husband to carer.

Michael touched on the difficulty of caring for his Mother when he explained there were times when he thought:

... 'why don't you just slip away mum'. You know, it's for her sake as well as ours and really, I suppose it was terribly selfish thing to do because you should try and preserve her life.

742-745

He admitted to having the same feelings for Julie:

... I feel that I've got to look after her, but I can understand there are times when I think, it would be better if Julie was not there(.)that's an awful thing isn't it. You know I- -she's restricted my life so much erm, that yes I feel I've got to look after her as such...

717-721

Michael is caught between sense of duty to care, and acknowledgement that the dementia is reducing quality of life for both him and his wife to the point when her death would be “*awful*” but “*better*” for both parties.

“Till death do us part”

Following on from the last sub-theme, Michael refers to the marriage vow as part of his duty to care: “*Till death do us part*” is one of the reasons why he has to look after Julie, even though he is no longer Julie’s husband in some respects, but her carer

Why do you feel that you need to look after her?

I don't know. Till death do us part and all that business I guess...

723-725

Anne also cites her wedding vows as obliging her to continue caring for him. This was poignantly summarised in the following extract.

'He's nothing like the man he was at all(.)but, till death us do part(.)so I gotta' put up with it'

Interview 1: 712-713

Anne's vow outweighs the distress she is experiencing: "*you just have to do it; you battle on*". It contributes to what seems like an inner conflict between supporting John and the negative impact of living with challenging behaviour.

Sometimes you feel as if you're going to break, you aint going to be able to cope(.)and then I wonder what'll happen to him if I didn't cope. So(.)you're fighting with your own emotions all the while.

Interview 2: 355-358

Anne is fighting her emotions to keep going for John's sake. She cannot "*break*", or who would care for him? In putting John's needs before her own, Anne shows self-sacrifice, resilience, and an enduring commitment to John. She is willing to risk breaking herself rather than the marriage vow.

Making sense of outsiders

This super-ordinate theme brings together how the outside world impinges on Anne and Michaels' experiences. There is a sense of isolation, with Anne describing how it is impossible for others understand if they have not lived through the experience. Michael is more accepting of the understanding of close friends, but still lives in a shrunken social world. Even family members struggle to be supportive. For both caregivers, their sons found the situation particularly difficult. The knowledge that there is something called 'ISB' and hence others who are also experiencing it is helpful for Anne.

"Outsiders"

"*Outsiders*" was a term used by Anne and reflected a view that other people who were not in her situation could not fully understand her situation:

'Cos they wouldn't really understand(.)a lot of people don't wanna' know do they. I do talk to me sister occasionally, but then they don't(.)understand when they're not in it do they. It's different being in a situation than talking about it...

Interview 1: 563-567

"*People don't wanna know*" suggests a feeling that other people are not interested or do not care. Even her sister cannot understand from the outside,

and she is not 'in it'. "Outsiders" can take themselves away from a difficult situation, whereas she has to stay.

Me and my son are very open with each other(.)yeah, but he only comes once a week you see. Like, he says, "Mum, he's getting on my nerves, I can't stand this". I Say, "You're only here one day a week" ... I don't know, he probably understands, but then again he can just get his coat on at the end of the day and walk away. I can't.

Interview1: 862-869

The use of 'only' implies that she feels her son does not visit enough. He can 'just get his coat' when he cannot "stand" John's behaviour, unlike her.

"Mum, you can't do that"

This sub-theme reflects the different views that other family members have and how Michael tries to make sense of this. Like Anne's son, Michael's son struggles to cope. However, his daughter shares Michael's practical approach.

...My daughter understands and she says 'oh, come on Mum, you can't do that', you know 'what's the problem' sort of thing, you know or 'how can I help you'. Erm, but my son would be mortified, and he is you know- -he just leaves it to me 'oh, I can't stand it, I'm offski'...

495-499

Michael's understanding of the difference between his son and daughter seems to be that their view of the behaviour influences how they respond to it. This may stem from their experiences growing up with their Mother.

Why do you think it's different with your daughter?

...my wife has been er, has been very active in the growing up of my daughter, you know, in all aspects of her growing up, you know erm, and, and, obviously has been involved in all her ...intimacies over the years...they are aware of each other's bodies aren't they, whereas my son doesn't want anything to do with my wife's body [laughs], you know, if he, if he saw her, er, when they were younger, if they passed on the landing, you know, he would cover up or whatever, you know what I mean. It's just something that, that Mother-Sons do,

whereas daughters don't, because they are fully aware of everything.

540-552

Michael's sense making suggests that his daughter is not uncomfortable with seeing her Mother's body because she is familiar with it. Julie has been "very active" in the growing up of his daughter and now the roles have reversed so that his daughter is providing support to her instead. It seems his son has always been uncomfortable and even "covered" himself up in front of his Mother. Perhaps the son feels shamed by the behaviour and would rather avoid any situation in which his or his Mother's body are exposed to one another.

Friends understand and strangers misconstrue.

Unlike Anne, Michael does feel that close friends can have understanding. Michael and Julie have retained a close group of friends. Whilst Michael avoids going to social situations that are unfamiliar, he seems to feel comfortable going to the local pub.

Erm, we, we probably go down to the local pub now and again, but that's about the best we can do...they are very used to Julie, erm and her behaviour and you know they look after her as much as me, because we've been going down for years and all that sort of business...so if she does have this problem of erm, stripping off, it's not, not a problem because they know it's going to happen as well.

220-229

He appears to be staying within a safe zone, living in a smaller world of friends and family and does not expose himself to many situations outside of this. Friends know the behaviour occurs and understand why. However, people who do not know Julie could make assumptions misconstruing the behaviour as sexual.

...she'd sort of takes her clothes off as I say erm, at inopportune moments and I think this would be construed as being sexual and it wasn't really...I was looking for that behaviour and I knew it was going to happen. And again, I think this would be erm, construed as probably

sexual if you did it, you know, erm in, in groups of people.

36-46

Why do you think people have that point of view, that they see somebody stripping and then thinks it's inappropriate sexual behaviour?

Erm(.)probably because it's erm(.)it, it(.)a lady removing her clothes I guess is sexually provocative, isn't it, to the younger person. Erm, well to- -even to me, if somebody, if somebody just suddenly starts taking their clothes off, erm, it's viewed as something sexual, you know.

307-315

Michael once again conveys views that disrobing would only be sexually provocative in a younger person. Interestingly, on this occasion he admits himself that he could view it in a sexual way. His thoughts on this may be related to the word “*suddenly*”. It suggests that if there is no context or reason and disrobing unexpectedly happens it may be construed as sexual, alluding to a wider societal attitude that this behaviour is associated with sexual connotations.

“You have to sort of put up with it by yourself”

This theme captures Anne’s feelings of isolation. Whilst Anne believes that talking about ISB is different from experiencing it, she acknowledges that there are benefits in being able to speak to others:

...You have to sort of put up with it by yourself, because(.)who can you talk to about(.)especially the sexual part, who can you talk to...Where it does you good to talk to people doesn't it, get it off your chest, but everyday people I can't.

Interview 1: 546-551

Talking allows Anne to offload some of her emotions, but the opportunity is not always available. Anne emphasises that the sexual aspect of John’s presentation is the most difficult to talk to others about. The only outlets to talk about ISB are John’s psychiatrist and a carer service:

...well I've got the care team. They ring me, but they usually ring me when I'm at home which I find it difficult to talk when he's there. But Dr Brown...Is brilliant he is. I can talk to him about anything.

Interview 1: 199-206

Anne finds it difficult to talk in front of John and there are limited opportunities to speak privately. There were long periods of time when Anne was coping alone. Her family can be dismissive and her social circle has also reduced.

I find people don't come anymore to see us, you know. Neighbours used to come, nobody don't come anymore. I don't think they know how to handle it, I don't know.

Interview 2: 373-376

As discussed, for Anne “outsiders” who have not lived through the experience themselves lack understanding, but knowing that there are others who live with ISB helped reduce feelings of isolation for Anne. In “telling it like it is” to a carer support worker, Anne first heard the term ‘ISB’. Giving the behaviour a “name” meant that she was not the only one experiencing it.

...when you got something like that, you think you're the only one you see, but obviously if it's got a name then it, it does go on...When it was just happening and like I hadn't heard the words inappropriate sexual behaviour, you just think it's something you gotta' put up with and(.)but, obviously if it's got a name then it's happening a lot, and there are other people having to put up with it the same as me.

Interview 1: 1065-1076

A: I feel sorry for 'em, but you know you're not the only one, so you're not alone in that way.

Interview 1: 1080-1081

4. Discussion

This study aimed to explore caregiver's experience of ISB whilst caring for their spouse with dementia. Two caregivers participated in the study and analysis of the data conveyed two different experiences of behaviour which could be

perceived as ISB. A tentative analysis across cases was conducted and revealed some convergence; both caregivers attempted to make sense of the behaviour in terms of its impact on them, its influence on their marriage and how it was interpreted by people outside of their relationships.

4.1 Discussion of results

'What the behaviour means to me' illustrated two different accounts; Anne experienced daily distress living with sexually harassing behaviours directed at her whilst Michael did not interpret his wife's disrobing behaviour as ISB. The experiences of the two caregivers in this study reflect gender differences noted in wider dementia literature which Ward *et al.* (2005) described as 'gendered dichotomy'; men are labelled as more sexually aggressive than females (Huong & Razali, 2013) and their sexual behaviour is likely to be pathologised (Hayward *et al.* 2012).

However, Michael acknowledged that Julie's disrobing behaviour could be construed as ISB by other people and used minimisation and avoidance to cope with this. Lazarus and Folkman, (1984) suggested that people adapt to distressing situations by adopting problem-focused or emotion-focused coping strategies. Emotion-focused coping (such as minimisation and distancing) may be helpful when a source of stress is outside a person's control; problem-focused coping (such as problem solving) is used to manage the problem causing distress (Lazarus & Folkman, 1984). These approaches are not a strict dichotomy, they are context dependent with people showing a mixture of problem and emotion focused traits (Schoenmakers *et al.* 2015). Whilst Michael pre-dominantly adopted a problem-focused approach as he felt he could control Julie's disrobing behaviour, when faced with the potential of it being viewed inappropriately by others he switched to emotion-focused coping (minimisation and avoidance). As he is not able to control the views of other people this approach may have served to protect him at these times. Anne experienced John's behaviour as unpredictable and adopted a more emotion-focused approach as the situation seemed to be out of her control. She moderated her distress by distancing the John she married from ISB, it was not her husband doing this to her. When Anne became aware that she could attempt to change the situation, she displayed

problem focused coping by seeking support from external sources (Brannen & Petite, 2008).

Furthermore, both distanced their respective partners from ISB by attributing it to dementia. Heider's, (1958) attribution theory suggests people will ascribe behaviour internally (under the control of the individual) or externally (out of an individual's control). Anne and Michael's external attribution reflects findings in other dementia studies (Hayward *et al.* 2012; Stokes *et al.* 2014), and has been termed the 'halo' effect, where the label of dementia absolves the person of responsibility for their behaviour (Golander & Raz, 2000 as cited in Archibald, 2002). Externalising the behaviour in such a way may protect caregivers; allowing them to view ISB as arising from circumstance rather than from the person, a notion which may be difficult to accept. There is much stigma associated with ISB (Robinson, 2003) and therefore understandable that caregivers want to distance themselves and their partners from such behaviour; attributing it to dementia is one way to achieve this. Indeed, once Anne became aware of the ISB label, this was confirmation to her that it was part of the illness because other people must display it. While this may serve to reduce emotional distress by not attributing responsibility for the upset to one's spouse, it also created a barrier for Anne challenging the ISB as she explained you cannot tell someone with dementia to "*clear off*".

External attribution was further demonstrated in 'The change in our relationship'. Both caregivers described no longer recognising their spouse and this has been captured in other dementia literature (Baikie, 2002; Gillies, 2012; Hayes *et al.* 2009; Pozzebon *et al.* 2016). Sweeting and Gilhooly, (1997) suggested that this loss occurs due to 'social death' which arises from the merging in dementia of a long term illness, old age and the loss of recognisable characteristics. Alternatively, Sabat and Harre', (1992) argue that loss of self-identity in dementia is likely due to the way in which others view that person and caregivers need to resist defining their relative in terms of the illness. For Anne and Michael, the loss of the person they once knew seemed compounded by ISB; potentially making it difficult not to define their spouse in terms of illness. They said that their partners would be "*horrified*" and "*mortified*" if they knew the behaviours they were displaying. As with external attribution, not viewing them as the same people may

be a way to psychologically distance their partner from this behaviour. Crisp, (1999) argues that survival of the self in dementia is impeded by stigmatising attitudes towards the illness; John and Julie's sense of self may further be eroded by the stigma associated with ISB.

The stigmatisation of ISB was also evident in 'Making sense of outsiders'. This possibly reflects wider negative social attitudes towards aging and sexuality (Benbow & Beeston 2012; Gott & Hinchliff, 2003) or that people just do not know how to respond to it and choose to avoid it. Stokes *et al.* (2014) note that stigma and fear lead to dementia being a hidden condition. This study finds that the addition of ISB in dementia seems to deepen this, as ISB is also taboo. Anne's interpretation that it is not possible to fully understand ISB without directly experiencing it gives some context for the fear and stigma that is felt from 'outsiders'. Michael found that when people did have an understanding of Julie's disrobing behaviour (i.e. his daughter and close friends) they were supportive. When he perceived a lack of understanding or awareness (i.e. his son and strangers) the behaviour was construed differently and led to embarrassment. Furthermore, ISB seemed to compound a shrinking social circle already affected by the progression of dementia (Robinson, 2003). Anne felt that others were not sure how to react or cope with the behaviour, so they chose to stay away; whereas Michael acknowledged the potential embarrassment of Julie's behaviour and chose not to expose himself to unfamiliar social situations. Thus, it seems that the stigma experienced by Anne and Michael was driven by a lack of awareness from other people. Indeed, the times they felt supported were when others recognised their difficulties; for Anne this was professional support and for Michael it was his daughter and the small group of friends who knew Julie.

Despite the negative and stigmatising impact of ISB, both caregivers remain committed to their partners. Social exchange theory suggests that individuals seek reward at minimal cost and enter relationships where there are equal outcomes for both partners (Vanyperen & Buunk, 1991). Applied to caregiving couples in dementia, it suggests that if a marriage is experienced as equitable before onset of the illness the caregiving spouse reciprocates because their partner has 'earned' care by being a good provider in the relationship (Braun *et al.* 2009; Loboprabhu *et al.* 2005). Whilst Anne and Michael may currently be

experiencing more 'cost' than 'reward', they both spoke positively of their pre-morbid relationship. With regards to social exchange theory, caregiving may be a 'cost' which balances out the 'reward' of their past relationship so they continue to care for their partners despite sacrificing their own needs. Loboprabhu *et al.* (2005) suggested caregiving spouses may gain a sense of pride in fulfilling their vows despite self-sacrifice. However, the conveyed narrative from 'The change in our relationship' was one of feeling trapped by these vows as it was their responsibility to provide care. Baikie, (2002) examined the impact of dementia on marriage and contested that if an individual with dementia enters formal care, their caregiving spouse may feel guilty for not being able to fulfil their marriage vows. Anne and Michael seemed to hold a fatalistic attitude and this is important to bear in mind; These two caregivers may feel they have no other option and it is solely their responsibility to care for the person.

In 'The change in our relationship', both caregivers described a loss of sexual intimacy, which has been noted elsewhere in dementia literature (Eloniemi-Sulkava *et al.* 2002; Pozzebon *et al.* 2016). Michael explained that he is not sexually attracted to Julie and for Anne, the sexual aspect of the relationship had become one sided and on John's terms. Eloniemi-Sulkava *et al.* (2002) found that for spousal caregivers, the most common negative sexual change was that the person with dementia was unable to pay attention to the spouse's sexual feelings and needs. This raises an interesting question, does ISB change the nature of a relationship or does the change in a relationship alter the view of sexual behaviour? Michael did not see Julie's disrobing as ISB; there was no longer a sexual aspect to their relationship and no sexual connotation to her behaviour. Anne acknowledged that she would like to have a sexual relationship with John; however, the relationship was no longer reciprocal, lacked mutuality and the love behind his behaviour had been replaced by aggression, from her perspective this made his sexual advances inappropriate.

4.2 Limitations

This study explored the accounts of two caregivers experiencing behaviour which could be perceived as ISB, therefore it offers an insight into the lived experience of this behaviour, but does not present findings that can be generalised to the broader population. IPA studies are not carried out with the expectation that

findings will necessarily generalise to a wider population, but rather to provide in-depth, idiographic accounts of a particular phenomenon (Smith & Osborn, 2003). As no published research for informal caregiver experience of ISB exists (Hayward *et al.* 2012; Stubbs, 2011), this study is important in developing the foundations for further research into this overlooked area.

The study stayed closed as possible to the homogeneity that is needed for IPA (Smith & Osborn, 2003) by only inviting spousal caregivers to participate, consequently other caregivers were not included such as other family members and friends who may provide alternative narratives regarding ISB. Furthermore, differences in age, race and culture were not explored, all factors which may influence how one makes sense of ISB and which future research could take up.

As caregivers volunteered to participate it could be argued that they felt confident and comfortable enough to discuss their experiences of ISB. Thus there is no representation of people who experience this phenomenon, but do not wish to talk about it. If the voice of these caregivers were to be heard they may narrate a different story as to how they make sense of ISB. The use of an anonymised diary, rather than face-to-face interviews may encourage other people to take part.

It has been argued that the concept of ISB focuses on the 'problem' behaviour and less on the bio-psycho-social factors which may be influencing it (Ward & Manchip, 2013). ISB in dementia may stem from biological changes such as deterioration in the brain leading to disinhibition or a psychological need for closeness (Higgins *et al.* 2013; Tsatali *et al.* 2011). A person may struggle to communicate their needs and expressing themselves through behaviours such as touching others may be misconstrued as being sexual in nature (Tsatali *et al.* 2011). The findings from the current study suggest that how the two caregivers made sense of ISB was based within the context of changes in their relationships with their respective partners. Youell *et al.* (2016) interviewed caregivers about changes in their relationship with spouses who had dementia and noted the importance of taking into account the wider relationship history and how sexuality fits in with this. Therefore, rather than situating ISB as something separate from the relationship, the current research could have been approached from a

position where caregivers spoke about possible relationship changes with the aim to discuss potential differences in their view towards sexual behaviour following these changes. This may have provided less of a focus on a 'problem' behaviour and more on the possible change in needs of the caregiver and the person with dementia. However, it is only with hindsight after completing the current research that the researcher more fully appreciates how ISB fits within the context of a relationship. Approaching the research in the exploratory way that it was conducted allowed the researcher to gain an appreciation of the limits of the concept of ISB and acknowledge how future research can be shaped around a focus on the change in relationship dynamics.

4.3 Future research

Despite the limitations of this small sample study, its findings are important in opening up this under-researched topic and contributes to a fledgling evidence base. To build on the current study a wider geographical net could be cast to increase both the number of approachable services and potential participants; hence the sharing of emergent themes from this study may prove useful to see how they fit in once a larger sample is recruited. Similar IPA studies focusing on different familial caregivers, age, race and culture may shine light on alternative narratives around ISB; Smith *et al.* (2009) suggest that as further IPA is conducted in a certain area it may illustrate a bigger picture for the given population.

Longitudinal research into spousal caregivers of someone with dementia has illustrated an evolving process of adaptability and a changing relationship (Lin *et al.* 2011). The caregiving experience is not static and may change over time. A longitudinal study may give a richer indication of caregivers' sense making of ISB over time and how they adapt and cope with this. The use of anonymised diaries may be useful for such research, which might also encourage caregivers who do not wish to discuss ISB face to face.

Part of Anne and Michael's sense making of ISB involved trying to understand the views of "outsiders"; people not living their experience. Whilst not living day to day as a caregiver, the reactions of "outsiders" in this study contributed to how the two caregivers made sense of ISB. Given the stigma surrounding ISB

(Robinson, 2003), it might prove useful to understand the experiences of “outsiders”; non caregivers such as friends who are exposed to it.

4.4 Clinical implications

This study gives a disturbing insight into the distressing burden of ISB for caregivers, and highlights the importance of providing support for them. Whilst there is limited generalisability of the findings, they may be helpful to spousal caregivers exposed to ISB and services who support them.

Qualitative research gives the opportunity for people to read the accounts of others who are in a similar situation and draw on aspects that may help them understand their own narratives (Cruickshank, 2012). Thus, this research may be beneficial firstly by illuminating that ISB is a reality for other people; merely knowing that there was such a thing as ISB was helpful for Anne. Secondly, the findings show the complexity of how people may experience ISB, for example, Michael did not interpret his wife’s behaviour as sexual, but nonetheless found it distressing to the point where he felt their quality of life was poor. Caregivers may empathise with the distress resulting from ISB directed at them or the stigmatisation of their partner’s behaviour being perceived as ISB by others. The research can be used to raise awareness of ISB in caregiving alongside documents such as ‘Sex and intimate relationships’ (Alzheimer’s Society, 2015) which highlights the taboo nature of discussing changes in sexual behaviour following onset of dementia.

The findings suggest that caregivers sense making of ISB can affect how they cope and relate to others (i.e. their partner and people close to them). Bearing this in mind, community staff may have to bracket what ISB means to them and attempt to gain an understanding from the caregiver’s point of view; this can then inform more tailored support. Furthermore, in staff training it may be useful to address discomfort in discussing ISB. Caregivers may differ in their willingness to talk about such behaviour and it may rely upon healthcare professionals to raise the topic, in a sense give ‘permission’ to discuss it. Reflective practice sessions may provide staff space to discuss the taboo surrounding ISB and help them understand their own concepts of the behaviour. Thompson and Pascal, (2012) note that reflective learning provides the opportunity to foster an ‘open-

mindful' approach to clinical practice with an aim to explore the underlying assumptions of a given situation.

This study has raised the issue that caregivers may feel trapped with a sense of obligation to their partners, even in distressing circumstances such as coping with ISB. Services may have to be aware of this and support caregivers in considering the decision to place loved ones into formal care by helping them manage psychological distress such as guilt and signposting to relevant support groups (Baikie, 2002; Hagen, 2001). Caregivers and their spouse could consider Advance Care Planning - an opportunity for people with dementia and their families to discuss future decisions (Dickinson *et al.* 2003). This could involve discussions about what should happen if potential behaviours such as ISB become too difficult to manage and may help reduce feelings of guilt in a caregiver if their partner has already agreed they may need formal care. This would need to be approached sensitively and will not be suitable for everyone (Dickinson *et al.* 2003), some people may not be willing to talk about potential behavioural changes as a result of dementia.

4.5 Conclusion

This study provides a unique glimpse into the lives of caregiver experiencing ISB; a neglected area within the literature. The caregivers in this study experienced stigma associated with dementia which was exacerbated by ISB. This seemed to arise from a lack of understanding from other people and highlights the importance of raising awareness of this behaviour. Whilst both caregivers experienced ISB differently, the high degree of distress disclosed by these essentially resilient people suggests a great need for service providers to learn more and provide appropriate support.

5. References

- Alagiakrishnan, K., Lim, D., Brahim, A., Wong, A., Wood, A., Senthilselvan, A., *et al.* (2005). Sexually inappropriate behaviour in demented elderly people. *Postgraduate Medical Journal*, 81(957), 463-466.
- Alzheimer's Society, (2014). *Dementia 2014 Infographic*. Retrieved 16th November 2014 from www.alzheimers.org.uk/infographic.
- Alzheimer's Society, (2015). *Factsheet: Sex and intimate relationships*. Retrieved 3rd May 2016 from www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1801
- Aminzadeh, F., Byszewski, A., Molnar, F. J., & Eisner, M. (2007). Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. *Aging and Mental Health*, 11(3), 281-290.
- Archibald, C. (2002). Sexuality and dementia in residential care-whose responsibility?. *Sexual and Relationship Therapy*, 17(3), 301-309.
- Baikie, E. (2002). The impact of dementia on marital relationships. *Sexual and Relationship Therapy*, 17(3), 289-299.
- Bauer, M., Nay, R., Tarzia, L., Fetherstonhaugh, D., Wellman, D., & Beattie, E. (2014). 'We need to know what's going on': Views of family members toward the sexual expression of people with dementia in residential aged care. *Dementia*, 13(5), 571-585.
- Benbow, S. M., & Beeston, D. (2012). Sexuality, aging, and dementia. *International Psychogeriatrics*, 24(07), 1026-1033.
- Bird, M. (1999). Challenging behaviour in dementia: A critical role for psychology. *Australian Psychologist*, 34(2), 144-148.
- Black, B., Muralee, S., & Tampi, R. R. (2005). Inappropriate sexual behaviors in dementia. *Journal of Geriatric Psychiatry and Neurology*, 18(3), 155-162.
- Bouman, W. P., Arcelus, J., & Benbow, S. M. (2006). Nottingham Study of Sexuality & Ageing (NoSSA I). Attitudes regarding sexuality and older people: A review of the literature. *Sexual and Relationship Therapy*, 21(02), 149-161.

- Brannen, C., & Petite, K. (2008). An Alternative Framework for Understanding Women's Caregiving Stress. A Qualitative Application of the Ways of Coping Model. *Journal of Health Psychology*, 13(3), 355-365.
- Braun, M., Scholz, U., Bailey, B., Perren, S., Hornung, R., & Martin, M. (2009). Dementia caregiving in spousal relationships: A dyadic perspective. *Aging and Mental Health*, 13(3), 426-436.
- Brodaty, H., Green, A., & Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*, 51(5), 657-664.
- Chan, W. C., Ng, C., Mok, C. C. M., Wong, F. L. F., Pang, S. L., & Chiu, H. F. K. (2010). Lived Experience of Caregivers of Persons with Dementia in Hong Kong: A Qualitative Study. *East Asian Archives of Psychiatry*, 20(4), 163-168
- Chang, K. H., & Horrocks, S. (2006). Lived experiences of family caregivers of mentally ill relatives. *Journal of Advanced Nursing*, 53(4), 435-443.
- Chien, L. Y., Chu, H., Guo, J. L., Liao, Y. M., Chang, L. I., Chen, C. H., & Chou, K. R. (2011). Caregiver support groups in patients with dementia: A meta-analysis. *International Journal of Geriatric Psychiatry*, 26(10), 1089-1098.
- Corbett, A., Stevens, J., Aarsland, D., Day, S., Moniz-Cook, E., Woods, R., *et al.* (2012). Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. *International Journal of Geriatric Psychiatry*, 27(6), 628-636.
- Crisp, J. (1999). Towards a partnership in maintaining personhood. In T. Adams, & C. L. Clarke (Eds.) *Dementia care: Developing partnerships in practice* (pp. 95-119). London: Bailliere Tindall.
- Cruickshank, J. (2012). Positioning positivism, critical realism and social constructionism in the health sciences: A philosophical orientation. *Nursing Inquiry*, 19(1), 71-82.
- Department of Health. (2009). *Living well with dementia: A national dementia strategy*. Retrieved 4th February 2014 from

www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy.

De Casterlé, B. D., Verhaeghe, S. T., Kars, M. C., Coolbrandt, A., Stevens, M., Stubbe, M., *et al.* (2011). Researching lived experience in health care: Significance for care ethics. *Nursing Ethics*, 18(2), 232-242.

Dickinson, C., Bamford, C., Exley, C., Emmett, C., Hughes, J., & Robinson, L. (2013). Planning for tomorrow whilst living for today: The views of people with dementia and their families on advance care planning. *International Psychogeriatrics*, 25(12), 2011-2021.

Eloniemi-Sulkava, U., Notkola, I. L., Hämäläinen, K., Rahkonen, T., Viramo, P., Hentinen, M., *et al.* (2002). Spouse caregivers' perceptions of influence of dementia on marriage. *International Psychogeriatrics*, 14(1), 47-58.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38(3), 215-229.

Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. (2005). The longitudinal effects of early behavior problems in the dementia caregiving career. *Psychology and Aging*, 20(1), 100.

Gergen, K. J. (1985). The social constructionist movement in modern psychology. *American Psychologist*, 40(3), 266.

Gillies, B. (2012). Continuity and loss: The carer's journey through dementia. *Dementia*, 11(5), 657-676.

Gott, M., & Hinchliff, S. (2003). How important is sex in later life? The views of older people. *Social Science & Medicine*, 56(8), 1617-1628.

Hagen, B. (2001). Nursing home placement: Factors affecting caregivers' decisions to place family members with dementia. *Journal of Gerontological Nursing*, 27(2), 44.

Hayes, J., Boylstein, C., & Zimmerman, M. K. (2009). Living and loving with dementia: Negotiating spousal and caregiver identity through narrative. *Journal of Aging Studies*, 23(1), 48-59.

Hayward, L. E., Robertson, N., & Knight, C. (2012). Inappropriate sexual behaviour and dementia: An exploration of staff experiences. *Dementia*, 12(4), 463-480.

Heider, F. (1958). *The Psychology of Interpersonal Relations*. New York: John Wiley & Sons.

Heru, A. M., Ryan, C. E., & Iqbal, A. (2004). Family functioning in the caregivers of patients with dementia. *International Journal of Geriatric Psychiatry*, 19(6), 533-537.

Higgins, A., Barker, P., & Begley, C. M. (2004). Hypersexuality and dementia: Dealing with inappropriate sexual expression. *British Journal of Nursing*, 13(22), 1330-1334.

Huong, L. M., & Razali, R. (2013). Hypersexuality in dementia: A case report. *ASEAN Journal of Psychiatry*, 14 (2), 170-174.

Johnson, C., Knight, C., & Alderman, N. (2006). Challenges associated with the definition and assessment of inappropriate sexual behaviour amongst individuals with an acquired neurological impairment. *Brain Injury*, 20(7), 687-693.

Joling, K. J., van Hout, H. P., Schellevis, F. G., van der Horst, H. E., Scheltens, P., Knol, D. L., *et al.* (2010). Incidence of depression and anxiety in the spouses of patients with dementia: A naturalistic cohort study of recorded morbidity with a 6-year follow-up. *The American Journal of Geriatric Psychiatry*, 18(2), 146-153.

Knight, C., Alderman, N., Johnson, C., Green, S., Birkett-Swan, L., & Yorstan, G. (2008). The St Andrew's Sexual Behaviour Assessment (SASBA): Development of a standardised recording instrument for the measurement and assessment of challenging sexual behaviour in people with progressive and acquired neurological impairment. *Neuropsychological Rehabilitation*, 18(2), 129-159.

Kristiansen, L., Hellzén, O., & Asplund, K. (2006). Swedish assistant nurses' experiences of job satisfaction when caring for persons suffering from dementia and behavioural disturbances. An interview study. *International Journal of Qualitative Studies on health and Well-being*, 1(4), 245-256.

Larkin, M., & Thompson, A. R. (2012). Interpretative phenomenological analysis in mental health and psychotherapy research. In Harper, D., & Thompson, A.R. (Eds.) *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp.101-116). West Sussex: Wiley-Blackwell.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3(2), 102-120.

Lazarus, R.S. & Folkman, S. (1984). *Stress, Appraisal and Coping*. New York: Springer Publishing Company.

Lin, M. C., Macmillan, M., & Brown, N. (2012). A grounded theory longitudinal study of carers' experiences of caring for people with dementia. *Dementia*, 11(2), 181-197.

Loboprabhu, S., Molinari, V., Arlinghaus, K., Barr, E., & Lomax, J. (2005). Spouses of patients with dementia: How do they stay together "till death do us part"? *Journal of Gerontological Social Work*, 44(3-4), 161-174.

O'Gorman, K., & MacIntosh, R. (2015). *Research Methods for Business & Management: A guide to writing your dissertation* (2nd edn). Oxford: Goodfellow Publishers Ltd.

Onishi, J., Suzuki, Y., Umegaki, H., Endo, H., Kawamura, T., Imaizumi, M., & Iguchi, A. (2006). Behavioral, psychological and physical symptoms in group homes for older adults with dementia. *International Psychogeriatrics*, 18(01), 75-86.

Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, H., & Sourtzi, P. (2007). Caring for a relative with dementia: Family caregiver burden. *Journal of advanced nursing*, 58(5), 446-457.

Pinquart, M., & Sörensen, S. (2006). Helping caregivers of persons with dementia: Which interventions work and how large are their effects? *International Psychogeriatrics*, 18(4), 577-595.

- Pozzebon, M., Douglas, J., & Ames, D. (2016). Spouses' experience of living with a partner diagnosed with a dementia: A synthesis of the qualitative research. *International Psychogeriatrics*, 28(4), 537–556.
- Princess Royal Carer's Trust (n.d.). *What is a Carer?* Retrieved 4th February 2014 from www.carers.org/what-carer.
- Princess Royal Carer's Trust (n.d.). *Why do carers need support?* Retrieved 4th February 2014 from www.carers.org/node/35517.
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18(1), 20-25.
- Robinson, K. M. (2003). Understanding hypersexuality: A behavioral disorder of dementia. *Home Healthcare Nurse*, 21(1), 43-47.
- Robinson, L., Clare, L., & Evans, K. (2005). Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples. *Aging & Mental Health*, 9(4), 337-347.
- Sabat, S. R., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society*, 12(04), 443-461.
- Sanders, S., Ott, C. H., Kelber, S. T., & Noonan, P. (2008). The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Studies*, 32(6), 495-523.
- Schoenmakers, B., Buntinx, F., & DeLepeleire, J. (2010). Supporting the dementia family caregiver: The effect of home care intervention on general well-being. *Aging and Mental Health*, 14(1), 44-56.
- Schoenmakers, E. C., van Tilburg, T. G., & Fokkema, T. (2015). Problem-focused and emotion-focused coping options and loneliness: How are they related?. *European Journal of Ageing*, 12(2), 153-161.
- Scott, A., Ryan, A., James, I. A., & Mitchell, E. A. (2011). Psychological trauma and fear for personal safety as a result of behaviours that challenge in dementia: The experiences of healthcare workers. *Dementia*, 10(2), 257-269.

- Selwood, A., Johnston, K., Katona, C., Lyketsos, C., & Livingston, G. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders*, 101(1), 75-89.
- 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(1), 39-54.
- Smith, J.A., Flowers, P. & Larkin, M. (2009), *Interpretative Phenomenological Analysis: Theory, method and research*. London: Sage.
- Smith, J.A. and Osborn, M. (2003). Interpretative Phenomenological Analysis. In J.A. Smith (Ed.) *Qualitative psychology: A practical guide to research methods*. (pp.51-80). London: Sage.
- Stokes, L. A., Combes, H., & Stokes, G. (2014). Understanding the dementia diagnosis: The impact on the caregiving experience. *Dementia*, 13(1), 59-78.
- Stubbs, B. (2011). Displays of inappropriate sexual behaviour by patients with progressive cognitive impairment: the forgotten form of challenging behaviour? *Journal of Psychiatric and Mental Health Nursing*, 18(7), 602-607.
- Sweeting, H., & Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health & Illness*, 19(1), 93-117.
- Takai, M., Takahashi, M., Iwamitsu, Y., Ando, N., Okazaki, S., Nakajima, K., *et al.* (2009). The experience of burnout among home caregivers of patients with dementia: Relations to depression and quality of life. *Archives of Gerontology and Geriatrics*, 49(1), e1-e5.
- Thompson, N., & Pascal, J. (2012). Developing critically reflective practice. *Reflective Practice*, 13(2), 311-325.
- Tsatali, M. S., Tsolaki, M. N., Christodoulou, T. P., & Papaliagkas, V. T. (2011). The complex nature of inappropriate sexual behaviors in patients with dementia: Can we put it into a frame? *Sexuality and Disability*, 29(2), 143-156.

- VanYperen, N. W., & Buunk, B. P. (1991). Equity theory and exchange and communal orientation from a cross-national perspective. *The Journal of Social Psychology, 131*(1), 5-20.
- Ward, R. F., & Manchip, S. (2013). 'Inappropriate' sexual behaviours in dementia. *Reviews in Clinical Gerontology, 23*(01), 75-87.
- Ward, R., Vass, A. A., Aggarwal, N., Garfield, C., & Cybyk, B. (2005). A kiss is still a kiss? The construction of sexuality in dementia care. *Dementia, 4*(1), 49-72.
- Yap, L. K. P., Seow, C. C. D., Henderson, L. M., & Goh, Y. N. J. (2005). Family caregivers and caregiving in dementia. *Reviews in Clinical Gerontology, 15*(3-4), 263-271.
- Youell, J., Callaghan, J. E., & Buchanan, K. (2016). 'I don't know if you want to know this': Carers' understandings of intimacy in long-term relationships when one partner has dementia. *Ageing and Society, 36*(05), 946-967.
- Zarit, S. H., & Femia, E. E. (2008). A future for family care and dementia intervention research? Challenges and strategies. *Aging and Mental Health, 12*(1), 5-13.

Part three: Critical Appraisal

The journey

Initially the research journey appeared to be straightforward, I had it all planned out with what seemed to be achievable deadlines (Appendix P); I soon learned that flexibility is necessary when conducting a piece of research. The experience has been fulfilling, even in the most difficult times. The reward of carrying out a piece of research that I am interested in has outweighed the stress of it all. With determination and excellent support, I have been able to overcome some of the hurdles I faced and adjust when necessary. I have had the opportunity to engage in interesting conversations with healthcare professionals and participants alike. All of which will set me in good stead as I prepare for my chosen path of working with people with dementia. The following reflective account details certain aspects of the research process which have stood out to me.

Conception

I left my role as an Assistant Psychologist (AP) working on a dementia inpatient ward. I enjoyed this work and whilst I thought of returning to it in the future, I decided to keep my options open, knowing that I was about to experience a wealth of opportunities through training. During my first year the cohort were given a number of different presentations from a number of potential research supervisors. There were so many options. When my current research supervisor presented and spoke about a study which explored staff experiences of Inappropriate Sexual Behaviour (ISB) on a dementia ward, it really grabbed my interest. That little part of me that enjoyed my work in the dementia setting was beginning to spark up. I was fully aware of the negative impact ISB could have on members of staff and also the attributions that they made. As an AP I heard on many occasions comments such as 'he can't help it' or 'it is part of the job' and I always wondered if any of the staff, under the surface, actually felt differently about the behaviour. During her presentation, my supervisor spoke about a project that she was interested in doing which would focus around the experiences of informal caregivers. I had no experience of working with informal caregivers, only family members who would visit the ward where I worked. This seemed like a good opportunity to do research in an area I was interested in at and at the same time learn about a context I was not familiar with. During an

initial meeting we discussed the lack of ISB research which involved informal caregivers, potentially due to the difficulty of accessing this population to talk about a sensitive topic (a difficulty I would come to learn was all too real). I took time to think about it: Is this a study I want to commit to? Given our discussion is it a study that is feasible? Why is this research important? The answer to the first question was a definite yes, I wanted to do something I was interested in; a previous supervisor had advised me to do something I cared about for my research as this would help me on the road to completion. It was a study that was possible, through discussions with my supervisors and healthcare professionals I felt it could be done. I knew it would be difficult, but still feasible. Finally, the research was important. The value of talking to caregivers about their experiences is noted throughout the literature, it seemed that understanding their perspective could help healthcare professionals to better support them (Chan *et al.* 2010; De Casterle *et al.* 2011).

Ethics

The first big hurdle I needed to overcome was getting the research approved by an ethics committee. Because of the sensitive nature of the topic and potential distress it may cause, I was anxious about attending a committee and the fear of my proposal being 'picked apart'. Upon reflection, part of me wondered to what extent the taboo nature of this topic extended, would it reach those who are in a position to approve such topics? However, I was also interested to hear their thoughts on the project and their ideas and suggestions in how to shape the research. I fully prepared myself with a proposal justifying why I chose to do this research, I had also spoken to caregivers to seek their thoughts and suggestions. I felt I had done the groundwork and was ready to defend why I was doing this particular piece of work. The meeting with the ethics committee ran smoothly. The people in attendance were interested in the project and acknowledged that exploration in this area was warranted. There were a few minor alterations, but aside from that the committee was fully on board and approved the research. This was a boost for my confidence and looking back what stood out for me was my preparation and the importance of doing so as this eased the whole process. Furthermore, it was reassuring to hear that such research was being encouraged and supported.

Literature review

During the initial stages of planning my literature review I carried out scoping searches. There is an abundance of research on challenging behaviour with both informal and formal caregivers, and with this numerous reviews. There isn't a lot of exploration of ISB and dementia (hence one of the reasons I chose to do the research) therefore I was unable to review this literature. It seemed a direct link between my research and the literature was not possible. I looked into challenging behaviour and other neurodegenerative diseases such as Parkinson's and multiple sclerosis. However, the literature seemed very limited and not enough to complete a literature review.

As I was reading through the literature a term that came up a number of times was job satisfaction. I completed an initial scope and found a few papers, which seemed promising. Whilst not directly linked to my research, it is relevant in terms of looking at a wider picture and factors other than challenging behaviour which may influence the care of people with dementia. Throughout the whole process, the literature review continually eluded me; I found it difficult to get a firm grasp on writing a coherent piece of work. The main difficulty was in the lack of conceptualisation of job satisfaction; at times it felt I was trying to make a mould out of jelly. Despite this, it was a good opportunity to highlight the need to develop a shared definition of job satisfaction and a scale that could be used more widely. I underestimated the work that needed to be dedicated to the literature review and this was one of the moments when I acknowledged that my planned achievable deadlines may not be met so easily. This required a reconfiguration of dates and using time I had dedicated to other parts of the thesis (and non-thesis time). Looking to the future I have gained an appreciation of the time and commitment that is required to write a literature review. Whilst I am yet to become more proficient, I have gained new competencies, such as effectively and systematically searching databases, which I hope will smooth out the process in the future.

The concept of ISB

The concept of ISB is potentially problematic, with a focus on the 'problem' behaviour it does not give space to consider the complexity of the relationship

between a caregiver and the person with dementia. Through conducting this research, I learned about the importance of considering the relationship context and how ISB fits into this. What came across strongly for me during the interviews and analysis was Anne and Michael's thoughts and feelings about their intimate relationships and the changes to these following the onset of dementia. Their views on the appropriateness of behaviour seemed to change in parallel with perceived changes in their marital relationships, for example, Anne believed that sexual behaviour was 'normal' within a marriage, but the lack of reciprocity in the relationship and forceful nature made John's advances inappropriate. The context around sexual expression changed for both couples and with it a different meaning was ascribed to the behaviour experienced by the two caregiving spouses. Similarly, in their study of intimacy in caregiving relationships of people with dementia, Youell *et al* (2016) noted that care relationships were situated in wider relational history and that sexuality is an important element of those histories.

Through speaking with the two caregivers in this study and developing the theme 'The change in our relationship' I gained a broadened view of what constitutes ISB. I had come from a behavioural based approach to ISB given my experiences on an inpatient setting for people with dementia who present with challenging behaviour, a different context where patients do not have ongoing intimate relationships. Without the context of a past relationship in a formal care setting there is the danger of expressions of sexuality being reduced to acts of sexual activity leading to the construction of it being a problem (Ward *et al.* 2005). Furthermore, in formal care settings it may be difficult for people with dementia to seek out intimacy as sexual expression is often prohibited, either in written policy or through the attitudes of care staff (Higgins *et al.* 2004). Thus, the concept of ISB seems to place the source of the behaviour in the person with dementia and does not consider their needs or changes in the intimate relationship between them and their caregiving partner. As Ward *et al* (2005) argued, it is essential to consider the complexity of sexuality and recognise it as an important aspect of personhood. Furthermore, one should keep in mind what sex and intimacy mean to the caregiving couple (Alzheimer's society, 2014) in order to understand what may be deemed as 'inappropriate' by them. For the two

caregivers in the current study the change in the nature of their relationship re-framed behaviour they deemed appropriate in the past.

A bio-psycho-social approach to ISB would allow one to consider the many factors that may be contributing to the behaviour being displayed. A biological view suggests that changes to the brain may have an impact on people's ability to express their needs, for example frontal damage in Frontal Temporal dementia may lead to loss of inhibitory control and impaired judgement (Tsatali *et al.* 2011). Furthermore, sexual expression may be driven by a psychological need for intimacy that a person with dementia has difficulties communicating or even that their behaviour is being influenced by the actions of those around them (Higgins *et al.* 2013) in the sense that they may misinterpret for example, a touch on the arm as an intimate connection. Thus, many behaviours deemed as sexually inappropriate and problematic could be 'normal' sexual expression complicated by changes in cognitive functioning, care needs and relationships (Ward & Manchip, 2013) and suggests the use of a more person centred approach to working with people who display such behaviour.

This reflects the Needs Driven Dementia-Compromised Behaviours (NBD) framework developed by Algase *et al.* (1996). The authors argue that challenging behaviour in dementia - such as ISB - arises from the expression of an unmet need. The framework takes into consideration a number of factors which may influence a person's behaviour such as cognitive skills, physical health difficulties, demographics and social environment; this information can be used to try and understand their needs and tailor a more individualised intervention (Algase *et al.* 1996). The NBD model alters the common view of challenging behaviour as disruptive, instead conceptualising it as an unmet need that, if responded to, may increase quality of life for those living with dementia (Kolanowski, 1999). Approaching ISB in this way may help us to understand how it fits within the context of changes in the relationship between the person with dementia and their caregiving spouse, instead of viewing it as a 'problematic' behaviour caused by dementia.

Recruitment

The recruitment Journey.

Of the whole research process, the part I found most difficult and which made me question whether or not I had chosen the right project was recruitment. I was under no illusion that it would be easy to get participants, but I did underestimate how difficult it would actually be. Initially I felt as though I was going into 'uncharted territory' and was being guided by the numerous services and professionals I had approached for advice. I was directed towards the carer service (CS) and younger people with dementia (YPD) team whom both agreed to support me with my project. I began recruitment in July 2015; up until October no caregivers expressed an interest in the project. Through continuous meetings, emails and telephone calls I kept in contact with both services. Neither had identified any caregivers who reported any experience of ISB, but as they were constantly getting new referrals there was always the chance that someone may come into the service. During the months of August and September 2015 I was also in contact with a Specialist Nurse and a Dementia Liaison Nurse both of whom worked within dementia services and had access to caregivers. Both services were unable to support me with my research as they were only in contact with caregivers for a short period of time who were likely to be distressed. In October 2015 the CS informed me that they had identified a caregiver who was willing to participate in the research. To say I was relieved was an understatement, although my anxiety was still high as I had another 2-5 participants to recruit.

I began a placement in an Older People- Community Mental Health Team (OP-CMHT) in October 2015 and this seemed like a good opportunity to extend my recruitment net. I received an amendment to the ethical approval in November 2015 to recruit through four OP-CMHT's across the county. This seemed to work well, through the OP-CMHT's six potential participants were identified. Unfortunately, none of them were able to take part for a number of reasons including being too busy with other responsibilities, already had been identified by the CS and one caregiver's husband passed away before she took part.

The CS identified a second participant in December 2015 and he agreed to take part in the project. This further alleviated my anxieties. At this stage my supervisors and I agreed that I aim for at least three participants. It seemed unlikely I was going to get six and three participants had been recognised as a suitable number for IPA (Smith & Osborn, 2003; Smith *et al.* 2009). Between January and March 2016 the YPD had given out two information packs and the CS three. A nurse within the YPD believed the two caregivers did not contact me as they were managing many others stressors in their lives. The CS did not receive any feedback after handing out the three information packs to caregivers, so it is not known why they chose not to take part. The CS had also posted the project in their newsletter and on their 'twitter' account without any joy.

In February 2016 I was informed of Join Dementia Research, a recruitment website. I contacted the website and they agreed to post my research. My research was posted on their site in the beginning of March 2016 which identified potential volunteers across the county where I had received ethical approval to carry out my research. Three people expressed an interest, however they did not meet the inclusion criteria (two cared for their Mother and one cared for their next door neighbour; they also explained that they had not experienced any form of ISB). Whilst my research was on this site I also kept in contact with the YPD, the CS and the four OP-CMHT's. In the last week of March and following conversations with my supervisors I decided to stop recruitment as the deadline for the project was close; we agreed that given the nature of IPA an analysis could be conducted with two participants (Smith *et al.* 2009). Furthermore, I had managed to gain very rich data, and conducted two interviews with one of the participants.

By the end of the recruitment process I was exhausted and disheartened. I knew recruitment was going to be difficult, but not to the extent that it was. Every now and then a potential participant was identified or someone expressed an interest, I always felt I was so close to getting another volunteer. Whilst I feel the research is worthwhile, there were moments when I came up against dead ends and I thought it probably was not the best choice for a doctoral thesis project with limited time constraints. Part of me thought that I should have chosen something where it would have been much easier to recruit participants and just get it

completed. But, it is a project I wholeheartedly believe in. The more difficult I found it to recruit people the more determined I was to do it; if I had difficulty looking for people to talk about their experience of ISB, how often does it come up when it is not being addressed?

Why was it so difficult?

There appeared to be a running theme throughout the whole project; on one hand healthcare professionals agreed that this research is needed, but on the other repeatedly reminded me that I had chosen a difficult topic. Thus I wondered if a block to recruitment was that staff may have felt there would be extra effort required on their part to identify potential participants. However, I felt that services were doing all they could amidst the pressured climates they were working in, the large caseloads they were managing and only having limited resources. Bearing this in mind, on several occasions I felt like I was 'hassling' staff and thus almost apologetic each time I contacted a service.

With the continued support of the services 10 people were identified during the research process. I discussed the low number of potential participants (it seemed low given the geographical spread of services across the whole county) with my supervisors and the services. Was it that not many people were experiencing ISB or were people unwilling to bring it up and talk about it? Some ideas that came up through discussions were: the potential of caregivers to just 'put up' with ISB as part of the dementia; caregivers manage numerous other practical issues such as finances which take up their attention; they may experience less severe forms of ISB which they feel do not warrant support from others; caregivers not feeling confident enough to bring it up or being embarrassed because of the taboo of talking about sex. Thus I found myself caught in a cycle where I believed research may help address and understand these issues, but without volunteers (possibly because of these issues) the research was difficult to do.

Other options available to me (and why I didn't pursue them).

During a meeting with my field and academic supervisors in November 2015 we discussed possible alternative solutions that I could pursue. The potential options were to widen the inclusion criteria to other family members or to interview staff members of the services involved in the research and explore their thoughts on ISB in the community. It was evident that I had a choice, carry on trying to recruit spousal caregivers in the community or switch my focus to one of the other options.

I chose not to pursue the first option as it would have reduced the homogeneity of the sample which is important for IPA (Smith & Osborn, 2003). Homogeneity may have been affected by potential differences in how spouses view sexual behaviour as opposed to say their children who may be less willing to acknowledge the sexual behaviour of their parents (Bauer *et al.* 2014). The differences between spousal and adult-children caregivers in dementia has also been noted elsewhere in the literature such as spouses may perceive higher levels of burden in caregiving (Pinquart & Sorensen, 2003) and adult-children are more likely to demonstrate denial in early stages of dementia (Meuser & Marwit, 2001). With regards to the second option of staff, this was a difficult choice for me to make. I knew staff would have been more readily available, so practically it may have been beneficial to go down this route. However, a part of me did not want to do this. I think to switch to staff would have negated the whole reason why I chose to do this research in the beginning. It would have confirmed what the literature was already telling me, that this particular area is too sensitive (Eloniemi-Sulkava *et al.* 2002).

I decided to keep going with my original project. I did not want to shy away from the difficulties of accessing this population and the problems with recruitment only served to confirm that this was a topic area which needed illuminated. I did not carry on blindly with what I was already doing. I had one participant I was due to interview and the option to recruit through the OP-CMHT's where I would soon be starting on placement. I had new avenues to pursue which gave me the opportunity to continue with the research I had set out to do.

What I will do differently.

As I look to build on this project in the future and increase the number of participants, two things I would like to do are widen the geographical net and also put a 'face to the researcher' (look for ways to approach caregivers directly). With regards to widening geographical location, this seemed to work in my project. As I broadened the number of services involved in the research, more potential participants were identified. With more time I would have liked to approach a different trust to identify appropriate services. I will also once again utilise JDR. This was a fantastic resource which helped bridge the gap between conducting research and identifying willing participants. Whilst my project was limited to one county (due to only having R&D approval in that area), with JDR there is scope to go national. With regards to putting a 'face to the researcher' I will look for opportunities to talk to groups of caregivers directly, such as working with the Alzheimer's Society to attend caregiver groups and present my research proposal. This will give me the opportunity to go into more detail about the research and put it into the context of why it is being done; I will be in a position where I can directly answer questions and hopefully alleviate any concerns. Furthermore, I will use the findings from my current project with the aim to highlight the possible benefits of talking about ISB in an anonymised research context (such as helping to raise awareness of the challenges of living with this behaviour).

Given the limitations of the concept of ISB as discussed previously, this may have had an impact on recruitment. Some caregivers may experience changes in how they view sexual behaviour displayed by the person they care for and find this a difficult experience, but they may not describe it as ISB; as was the case with Michael. Going forward, the research could be framed as exploring changes in the relationship between a spousal caregiver and the person they care for, with the aim to discuss any changes in how caregivers view sexual expression. This may encourage people to take part who experience forms of ISB, but do not necessarily describe it using this concept; furthermore, this would allow the researcher to explore how sexual expression is viewed within the context of changes in a relationship.

Interviewing

Before carrying out interviews with caregivers, I was able to conduct pilot interviews with my field supervisors and two AP's who worked on an in-patient dementia unit; each person drew on their experiences of ISB whilst working in the service. Interestingly, each of the volunteers sometimes spoke about unrelated topics. I discussed this with my field supervisor and the possibility of caregivers going into a 'safe zone'. As it is a sensitive topic, people may only feel comfortable talking about it for so long before naturally going back into conversations which make them feel more at ease. Going into the interviews with participants I tried to be conscious of this oscillating process occurring and giving people space to move between talking about ISB and neutral topics.

During the first research interview with Anne, I fought a constant urge to switch into my clinical role. Anne spoke about the distress she experienced on a daily basis as her husband was unrelenting with sexual behaviour directed at her. She did not talk too much about neutral topics and the interview felt very much like her life, saturated by ISB. It seemed like this was her opportunity to talk about it in detail and she wanted to communicate as much as she could in the time we had. Whilst I did not adopt my clinical role and managed to keep on my 'research head', I drew on my clinical experience to check in with how she was feeling and get an idea of the support she had available. I had a discussion with one of my supervisors about this urge to switch into a clinical role. The conversation was helpful to remind me that first and foremost I am a trainee clinical psychologist so it would be hard not to slip into this; particularly given the sensitive and distressing topic I was talking to people about.

Whilst Michael did not view his wife's disrobing behaviour as ISB, he acknowledged that others could and was happy to talk about this. Given the context of recruitment difficulties it seemed justified to interview him and I thought it would be interesting to talk to someone who experienced behaviour which could be considered as ISB by other people. The necessity of being aware of my own context and beliefs was important to consider when conducting this interview. My view is that disrobing can be sexual in nature and inappropriate; I bracketed this in the interview and was careful not lead the interview based on my belief.

Therefore, I only referred to the behaviour being construed as ISB when Michael acknowledged this first. To help with this, I again drew on my clinical experience. There have been moments in therapy sessions when something has resonated with me and over the course of training and through experience I have learned to acknowledge, put to one side and reflect upon such things in supervision.

Managing risk

During her first interview Anne explained that she sometimes worried that John's behaviour could escalate and he may hurt her. She said that she was receiving support from healthcare professionals and there were plans to alter John's medication; I believed there was no immediate risk to her safety. However, following the interview I had an uncomfortable feeling which stayed with me for a number of days, particularly as I typed up the transcript and once again connected with Anne's story. As I processed these feelings, I knew it was concern for Anne's well-being and safety. I contacted my supervisors and explained my concerns for Anne; I continued to believe there was no immediate risk, but she was in a situation which could escalate. I completed the transcript quickly, sent it to my supervisors to read and we met up to discuss this issue. They agreed that there seemed to be no immediate risk, but it would be worth contacting Anne to have a discussion about getting extra support, particularly if there was potential for escalation of John's behaviour. I met up with Anne again a few weeks after the interview had taken place. She explained that John's medication had recently changed and he was no longer displaying ISB or aggressive behaviour. She reported that she was coping much better on a daily basis and no longer felt threatened. We discussed options for other support if she needed it, but she was happy with the help she was receiving from John's psychiatrist and the carer service. I very much felt relieved after meeting with Anne and hearing that her living situation had seemed to improve. There was tension between my position as a researcher (my main role in this study) and my role as a clinician with a duty of care. With support from my supervisors I went beyond the role of a researcher to meet up with Anne again and discuss my concerns; I continue to believe I made the right decision. Going forward I aim to hold in mind that the two roles are complementary to one another, not a strict dichotomy.

IPA analysis

I am a novice in qualitative research and my only previous experience of carrying out such work was using Thematic Analysis in my second year service evaluation. I knew qualitative research was the best fit as my aim was to interview caregivers about their experiences. Throughout the course of teaching I was made aware of several qualitative methods which can be adopted. IPA seemed to be appropriate as its focus was on exploring the lived experience of a given phenomenon. I was also drawn by the position it takes in which the participant, not the researcher is expert and it allows the researcher to explore the way a person makes sense of their experiences, giving a possible inside perspective of their cognitive world (Biggerstaff & Thompson, 2008; Dickson *et al.* 2008). Whilst I have experienced ISB, I have never been a familial caregiver. The people I intended to talk to were the experts and I wanted to learn from them.

Carrying out the analysis demonstrated to me the power of qualitative research and why reflexivity is necessary. Reflecting upon my interviews with Anne, I had caught a glimpse of her world and it had an emotional impact on me. Whilst analysing the data I felt myself focusing on the threatening aspects of Anne's account of ISB. Reflexivity helped me understand why I was drawn to this part of the narrative. I related this to my experience of addressing the potential risk to Anne and also my time on the inpatient ward as an AP where I witnessed the distress that ISB caused some members of staff. I reminded myself that whilst this was important, it was part of Anne's story and wanted to make sure I got this across in the context of struggling with the changes in her relationship and social isolation that she also felt. Thus I found myself engaged in the process of the hermeneutic circle as described by Smith *et al.* (2009) which suggests to understand a 'part' one must look at it in the context of the 'whole', and to understand the 'whole', one must examine the sum of its parts. This process helped me move away from one part of the account I was drawn to (because of my previous experiences) and look at how it fitted in with other parts of her story. From this I was able to make links such as how her attribution of ISB to dementia seemed to be a way of coping with the behaviour ('What the behaviour means for me') and related to her views that John was no longer the same man because of the illness ('The change in our relationship'); this may have served to protect

them both from the stigma associated with the behaviour ('making sense of outsiders') because it wasn't her husband displaying it.

The analysis involved a lot of circular processing as I moved back and forth during the development of themes, repeatedly checking that they were evidenced in the data; I wanted to stay true to Anne and Michael's sense making of ISB. To help this process I was part of a support group with other trainees using qualitative methodology. I also met with one of the trainees occasionally on a one-to-one basis to swap and look at sections of our transcripts and discuss ideas. This was further aided by supervision sessions which gave me space to reflect on my interpretations. All of this was a valuable experience, allowing me to shape my ideas and put my own 'stamp' on the analysis. I am aware that my interpretation of the results is one of many possible, but enhancing the quality of my analysis through discussions with others helped me share what I feel is a meaningful interpretation of the experiences of caregivers. Going forward I would like to conduct qualitative research again, particularly to develop this project, and I'll hold in mind the importance of talking to others during the analysis stage; I will view it as an opportunity to step back from the data, check the interpretations make sense and that themes are evidenced in the words of participants.

Furthermore, I acknowledge that my findings may have been different if I was analysing more than two cases. I tentatively suggested convergence across these cases via the super-ordinate themes and some of the findings were reflected in wider literature. However, additional evidence from other caregivers may have further illuminated and supported these similarities (Smith & Osborn, 2003) or even led to the identification of other themes. I will be also mindful of the potential to be engulfed by data with a larger number of participants and seek support where I can as at times I felt quite overwhelmed by the data from three transcripts (feelings which were helpfully contained in supervision).

Concluding thoughts and the future

As I now come to the end, I feel physically and emotionally drained, but it has all been worth it. In the midst of carrying out this research I often lost sight of how much I had done and the goals I was aiming for; sometimes it was too easy to get caught up in the high volume of work and balancing this with clinical work and

a personal life. Having these experiences validated by other trainees as they too fought their own battles was reassuring, it very much felt like a 'rite of passage' on my way to becoming a clinical psychologist. From the early discussions of what the project would look like through the turbulence of recruitment and onto the daunting task of bringing it all together in the write up, it is only now, as I stand on the brink of completion that I can look back at all I have achieved. Numerous lessons were learnt about carrying out research including the necessity of preparation, the need for flexibility, and recognising personal limitations and when to seek support. Whilst I am yet to master research skills, I believe I have set a foundation in which I can confidently conduct future research. I am keen to disseminate my findings and will be in a fantastic position to build on this project as my first post following training is on a dementia ward which actively encourages research. More so, when I meet family members of people who have been admitted onto the ward, the glimpse I have caught into the lives of caregivers may help me understand and appreciate their journey a little better.

References

Alzheimer's Society, (2015). *Factsheet: Sex and intimate relationships*. Retrieved 3rd May 2016 from

www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1801

Algase, D. L., Beck, C., Kolanowski, A., Whall, A., Berent, S., Richards, K., *et al.* (1996). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer's Disease and Other Dementias*, 11(6), 10-19.

Bauer, M., Nay, R., Tarzia, L., Fetherstonhaugh, D., Wellman, D., & Beattie, E. (2014). 'We need to know what's going on': Views of family members toward the sexual expression of people with dementia in residential aged care. *Dementia*, 13(5), 571-585.

Biggerstaff, D., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology*, 5(3), 214-224.

Chan, W. C., Ng, C., Mok, C. C. M., Wong, F. L. F., Pang, S. L., & Chiu, H. F. K. (2010). Lived Experience of Caregivers of Persons with Dementia in Hong Kong: A Qualitative Study. *East Asian Archives of Psychiatry*, 20(4), 163-168

De Casterlé, B. D., Verhaeghe, S. T., Kars, M. C., Coolbrandt, A., Stevens, M., Stubbe, M., *et al.* (2011). Researching lived experience in health care: Significance for care ethics. *Nursing Ethics*, 18(2), 232-242.

Dickson, A., Knussen, C., & Flowers, P. (2008). 'That was my old life; it's almost like a past-life now': Identity crisis, loss and adjustment amongst people living with Chronic Fatigue Syndrome. *Psychology and Health*, 23(4), 459-476.

Eloniemi-Sulkava, U., Notkola, I. L., Hämäläinen, K., Rahkonen, T., Viramo, P., Hentinen, M., *et al.* (2002). Spouse caregivers' perceptions of influence of dementia on marriage. *International Psychogeriatrics*, 14(01), 47-58.

Higgins, A., Barker, P., & Begley, C. M. (2004). Hypersexuality and dementia: Dealing with inappropriate sexual expression. *British Journal of Nursing*, 13(22), 1330-1334.

- Kolanowski, A. M. (1999). An overview of the need-driven dementia-compromised behavior model. *Journal of Gerontological Nursing*, 25(9), 7-9.
- Meuser, T. M., & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist*, 41(5), 658-670.
- Pinquart, M., & Sörensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 58(2), 112-128.
- Smith, J.A., Flowers, P. & Larkin, M. (2009), *Interpretative Phenomenological Analysis: Theory, method and research*. London: Sage.
- Smith, J.A. and Osborn, M. (2003). Interpretative Phenomenological Analysis. In J.A. Smith (Ed.) *Qualitative psychology: A practical guide to research methods*. (pp.51-80). London: Sage.
- Tsatali, M. S., Tsolaki, M. N., Christodoulou, T. P., & Papaliagkas, V. T. (2011). The complex nature of inappropriate sexual behaviors in patients with dementia: Can we put it into a frame? *Sexuality and Disability*, 29(2), 143-156.
- Ward, R. F., & Manchip, S. (2013). 'Inappropriate' sexual behaviours in dementia. *Reviews in Clinical Gerontology*, 23(01), 75-87.
- Ward, R., Vass, A. A., Aggarwal, N., Garfield, C., & Cybyk, B. (2005). A kiss is still a kiss? The construction of sexuality in dementia care. *Dementia*, 4(1), 49-72.
- Youell, J., Callaghan, J. E., & Buchanan, K. (2016). 'I don't know if you want to know this': Carers' understandings of intimacy in long-term relationships when one partner has dementia. *Ageing and Society*, 36(05), 946-967.

Appendices

Appendix A – Author guidelines for target journal ‘Aging and Mental Health’

Taken from:

<http://www.tandfonline.com/action/authorSubmission?journalCode=camh20&page=instructions#.Vyef1OT2bIU>

Please follow the link above for full guidelines.

Aging & Mental Health is an international peer-reviewed journal publishing high-quality, original research. All submitted manuscripts are subject to initial appraisal by the Editor and if found suitable for further consideration, to peer-review by independent anonymous expert referees. All peer review is double blind and submission is online via [ScholarOne Manuscripts](#). We encourage the submission of timely review articles that summarize emerging trends in an area of mental health or aging, or which address issues which have been overlooked in the field. Reviews should be conceptual and address theory and methodology as appropriate.

Aging & Mental Health considers all manuscripts on the strict condition that

- the manuscript is your own original work, and does not duplicate any other previously published work, including your own previously published work.
- the manuscript is not currently under consideration or peer review or accepted for publication or in press or published elsewhere.
- the manuscript contains nothing that is abusive, defamatory, libellous, obscene, fraudulent, or illegal.

This journal is compliant with the Research Councils UK OA policy. Please see the licence options and embargo periods [here](#).

1. General guidelines

- Manuscripts are accepted only in English. Any consistent spelling and punctuation styles may be used. Please use single quotation marks, except where ‘a quotation is “within” a quotation’. Long quotations of 40 words or more should be indented without quotation marks.
- Manuscripts may be in the form of (i) regular articles not usually exceeding **5,000 words** (under special circumstances, the Editors will consider articles up to 10,000 words), or (ii) short reports not exceeding **2,000 words**. These word limits **exclude** references and tables. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.
- Manuscripts should be compiled in the following order: title page (including Acknowledgments as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).
Please supply all details required by any funding and grant-awarding bodies as an

Acknowledgement on the title page of the manuscript, in a separate Funding paragraph, as follows:

For single agency grants:

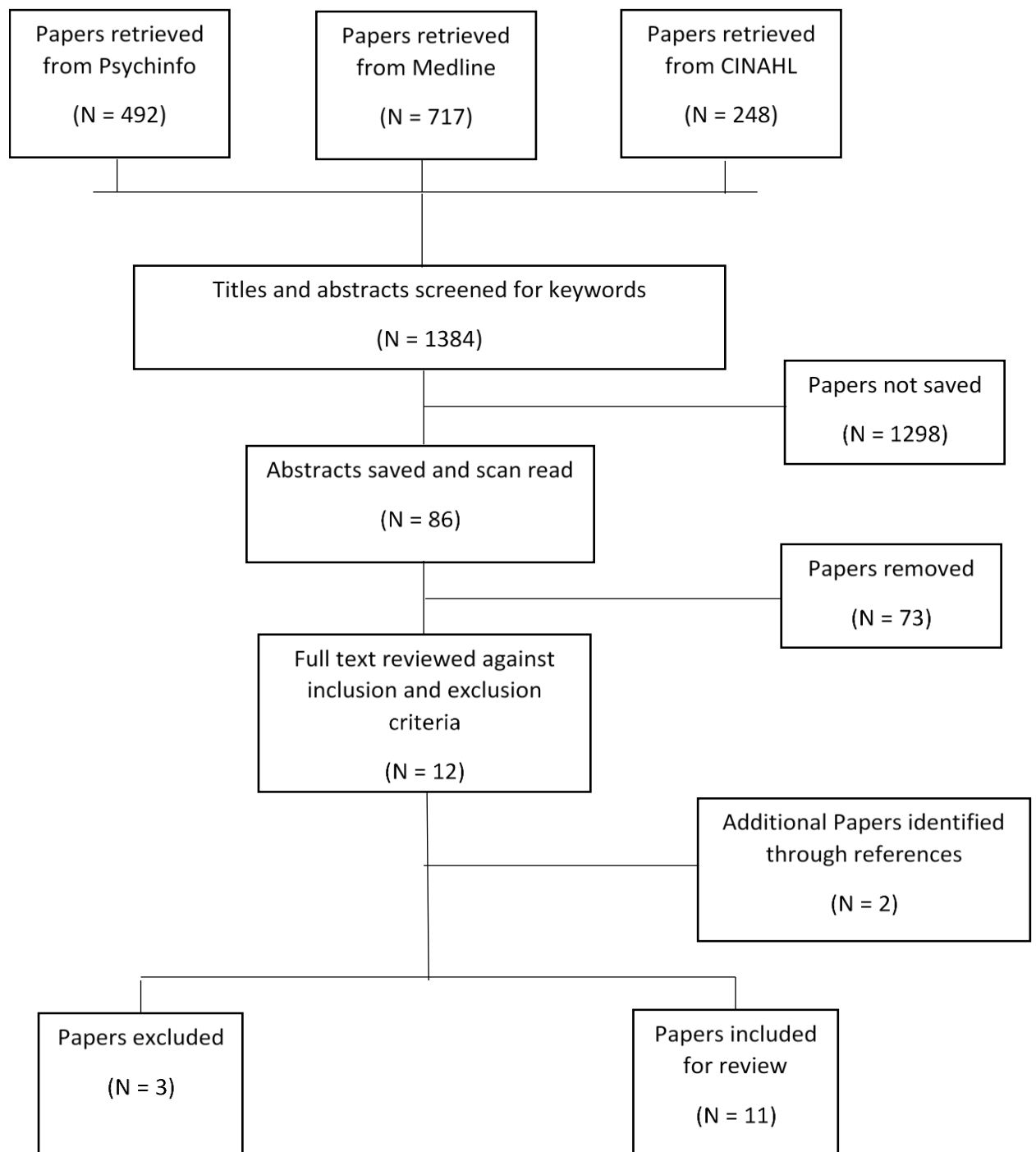
This work was supported by the <Funding Agency> under Grant <number xxxx>.

For multiple agency grants:

This work was supported by the <Funding Agency #1> under Grant <number xxxx>; <Funding Agency #2> under Grant <number xxxx>; and <Funding Agency #3> under Grant <number xxxx>.

- Structured [Abstracts](#) of not more than 250 words are required for all manuscripts submitted. The abstract should be arranged as follows: Title of manuscript; name of journal; abstract text containing the following headings: Objectives, Method, Results, and Conclusion.
- Each manuscript should have 3 to 5 [keywords](#).
- Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance [here](#).
- Section headings should be concise. The text should normally be divided into sections with the headings Introduction, Methods, Results, and Discussion. Long articles may need subheadings within some sections to clarify their content.
- All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.
- All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.
- Biographical notes on contributors are not required for this journal.
- Authors must also incorporate a [Disclosure Statement](#) which will acknowledge any financial interest or benefit they have arising from the direct applications of their research.
- For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms must not be used.
- Authors must adhere to [SI units](#). Units are not italicised.
- When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.
- Authors must not embed equations or image files within their manuscript.

Appendix B - Process of selection for papers to be reviewed (Figure 1)



Appendix C – Data extraction form

Article Number:		
Title:		
Author (1 st only):		
Publication Date:		
Journal:		
Volume:	Number:	Pages:
Keywords / Definitions		
Aims:		
Sampling / Participants: <i>(Total number of participants? Age range, who was studied, how was the sample recruited? Response rate?)</i>		
Study Type / Design: <i>(Randomized allocation?)</i>		
Outcomes and Measures: <i>(What outcomes are being measured? What measurements are used? Are measures validated? At what time points are measures completed self-report or clinician-rated?)</i>		
Analysis: <i>(What statistical methods were used?)</i>		
Findings		
Validity / Reliability:		
Conclusions: <i>(What do the findings mean? Generalisability? Implications & Recommendations?)</i>		
Additional Comments:		

Appendix D – Quality appraisal tool (Table 1)

Reporting	Yes (1)	No (0)	Unable to determine (0)
Is the hypothesis/aim/objective of the study clearly described?			
Are the main outcomes to be measured clearly described in the Introduction or Methods section?			
Are the characteristics of the patients included in the study clearly described?			
Are the main findings of the study clearly described?			
Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?			
External Validity			
Were the subjects asked to participate in the study representative of the entire population from which they were recruited?			
Internal validity			
Were the statistical tests used to assess the main outcomes appropriate?			
Were the main outcome measures used accurate (valid and reliable)?			
Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?			
Study design			
To what extent can the study identify causality?			
Scores differentiate between cross sectional, prospective/longitudinal and experimental designs.			
Total Score			

Appendix E – Summary of reviewed studies (Table 2)

Author(S)/Year/ Location	Aim of the study	Study design Analysis of job satisfaction variable.	Sample	Setting type	Job satisfaction measure Author Chronbach's alpha (CA)	Notable findings	Limitations
Brodaty <i>et al.</i> (2003) Australia	To explore the association between the attitudes, strain and satisfaction of nursing home staff working in dementia care.	Cross sectional. Pearson's product moment correlations.	Nurses and nursing assistants. N = 253 Mean age- 40.43 Gender %- Female 91.5 Male 8.5	Nursing homes.	Swedish Satisfaction with Nursing Care and Work Assessment Scale. (SNCW) (Hallberg <i>et al.</i> 1993) CA - 0.857	Staff who had negative attitudes and viewed the care recipients less positively had lower levels of strain and job satisfaction, compared to those who held positive attitudes.	Job satisfaction was not operationalised; thus it is not clear what the authors understood the concept to be. Limited generalisability due to opportunistic sampling and no inclusion/exclusion criteria. Distribution of scales was carried out by unit managers; therefore, authors could not calculate response rate. Participants completed behavioural rating scales on all residents which may have influenced their responses on attitude and satisfaction scales.
Hirata and Harvath (2015) Japan	Examined the relationship between caregiver's exposure to aggression and their occupational stress (job burnout, job satisfaction and intention to resign).	Cross sectional. Multiple regression.	Direct care workers N = 129 Age range (no mean) <30 – >60 Gender %- Female 68.2 Male 31.8	Special Dementia Unit	Kahana's Measure of Job Satisfaction of formal caregivers. (Tojo & Maeda, 1985; as cited in Hirata & Harvath, 2015) CA - 0.70	There were significant negative correlations between job satisfaction and aggression. Staff who experienced higher levels of aggression had lower levels of job satisfaction.	Operationalised aggression and stress, but not job satisfaction. Only used the job content subscale of the job satisfaction measure and excluded the salary/co-workers subscale; thus these aspects of satisfaction were not captured. Generalisability limited by opportunistic sampling.

Appendix E – Summary of reviewed studies(Continued).

Author(S)/Year/ Location	Aim of the study	Study design Analysis of job satisfaction variable.	Sample	Setting type	Job satisfaction measure Author Chronbach's alpha (CA)	Notable findings	Limitations
Isaksson <i>et al.</i> (2009) Sweden	This study aimed to explore the relationship between aggression of individuals with dementia and different factors including job satisfaction.	Cross sectional. Correlation analysis followed by discriminant analysis.	Nurses and nursing assistants N = 364 Age- Not detailed Gender %- Not detailed	Dementia units within nursing homes.	Job Satisfaction Questionnaire (Ekvall, 2001; as cited in Isaksson <i>et al.</i> 2009) CA – 0.73–0.89	Staff working in units with a high prevalence of aggression demonstrated lower job satisfaction than those working with less exposure to aggression.	Aggression measured as physical attacks and verbal threats, but no definition of job satisfaction. Generalisability limited by opportunistic sampling. Distribution of scales was carried out by unit managers; therefore, authors could not calculate response rate.
Robison and Pillemer (2007) USA	The authors investigated the differences in staff outcomes (including job satisfaction) between special care units (SCU's) for dementia and non-SCUs	Cross sectional survey (Data collected from two previous intervention studies). Bivariate analysis followed by stepwise regression.	Nurses and nursing assistants N = 352 Mean age-40.46 Gender %- Not detailed	SCU's and nursing homes.	Generic Job Satisfaction Scale (Macdonald & MacIntyre, 1997) CA - 0.77	Job satisfaction of staff was found to be higher on SCUs compared to non-SCUs. Greater job satisfaction seemed to depend on the working relationships with co-workers, supervisors and family members.	Data analysed was from randomly sampled populations, however was taken from older studies limiting generalisability. Job satisfaction was not operationalised. Data taken from studies which used identical recruitment strategies and data collection. However, the comparison of data did not account for potential differences in residents between the two types of unit.

Appendix E – Summary of reviewed studies(Continued).

Author(S)/Year/ Location	Aim of the study	Study design Analysis of job satisfaction variable	Sample	Setting type	Job satisfaction measure Author Chronbach's alpha (CA)	Notable findings	Limitations
Sjogren <i>et al.</i> (2015) Sweden	The authors investigated the relationship between staff characteristics, work environment and person centred care in nursing staff working in residential care units.	Cross sectional. Pearson's product moment correlations, followed by stepwise regression.	Nurses and nursing assistants N = 1169 Mean age- 45.8 Gender %- Female 95.2 Male 4.8	Residential care including nursing homes and special care units for people with dementia.	SNCW (Hallberg <i>et al.</i> 1993) CA – 0.71	High levels of person centred care was associated with higher job satisfaction, lower job strain and more supportive environments.	Job satisfaction was not operationalised. Large sample and wide geographical spread (across Sweden), but generalisability limited due to opportunistic sampling. Did not acknowledge and account for potential differences between types of care setting.
Te Boekhorst <i>et al.</i> (2008) Holland	This study aimed to investigate the difference between group living homes and traditional nursing homes in relation to job satisfaction and burnout.	Cross sectional. Multilevel linear regression analysis.	Nurses N = 380 Mean age- 40 Gender %- Female 93.4 Male 6.6	Group living homes and nursing homes.	Job Satisfaction subscale of the Leiden Quality of Work Questionnaire - LQWQ (van der Doef & Maes, 1999) CA – 0.86	Staff working in group living homes displayed higher job satisfaction than staff in traditional nursing homes. Higher levels of job satisfaction were associated with low job demands and high control and support.	Job satisfaction was not operationalised. Generalisability limited by opportunistic sampling. Potential differences in residents (e.g. level of needs) between the two types of care setting were not accounted for. The sub-scale of the LQWQ only measures four items, therefore several facets of job satisfaction would have been missed.

Appendix E – Summary of reviewed studies(Continued).

Author(S)/Year/ Location	Aim of the study	Study design Analysis of job satisfaction variable	Sample	Setting type	Job satisfaction measure Author Chronbach's alpha (CA)	Notable findings	Limitations
Van Beek <i>et al.</i> (2011) Holland	This study aimed to explore the relationship between job satisfaction and social support.	Cross sectional. Spearman's rho correlations followed by multilevel regression analysis.	Nursing and care assistants N = 417 Mean age- 38.2 Gender %- Female 95.3 Male 4.7	Dementia units within nursing homes.	Maastricht Work Satisfaction Scale for Healthcare (MASGZ) (Landeweerd <i>et al.</i> 1996; as cited in van Beek <i>et al.</i> 2011) CA – 0.88	Job satisfaction was positively and significantly correlated with the number of staff on a unit. Communication across staff was easier in small groups. Interaction between members of staff was positively associated with job satisfaction, but not significant.	Job satisfaction not operationalised. Generalisability limited by opportunistic sampling. Communication between staff in the units was not measured with a standardised scale. Participants only answered two questions in relation to this.
Wallin <i>et al.</i> (2012) Sweden	To explore variables associated with job satisfaction in residential care.	Cross Sectional. Multiple linear regression analyses.	Nursing assistants N = 225 Mean age- 44.1 Gender %- Female 86.4 Male 13.6	Residential homes and SDU's.	General - Job Satisfaction Questionnaire (Ekvall, 2001; as cited in Wallin <i>et al.</i> 2012) CA – 0.94 Context specific - Psychosocial Aspects of Job satisfaction Questionnaire. Engstrom <i>et al.</i> (2006) CA – 0.92	High general and context-specific job satisfaction was positively associated with personalised care and negatively associated with caregiver distress.	Provided a definition of job satisfaction, but not person centred care. Thus it is not clear what person centred care entailed in this study. Generalisability limited by opportunistic sampling. There was high drop out and the job satisfaction of these participants was not captured.

Appendix E – Summary of reviewed studies(Continued).

Author(S)/Year/ Location	Aim of the study	Study design Analysis of job satisfaction variable	Sample	Setting type	Job satisfaction measure Author Chronbach's alpha (CA)	Notable findings	Limitations
Willemse <i>et al.</i> (2012) Holland	To explore if peer and supervisor support was able to buffer the negative effects of demands on job satisfaction.	Cross sectional (Data collected from a previous study). Multilevel linear regression analysis.	Nurses and nursing assistants N = 1093 Mean age- 43.0 Gender %- Not detailed	Range of settings including nursing homes, care homes and specialised dementia units.	Job Satisfaction subscale of the Leiden Quality of Work Questionnaire (van der Doef & Maes, 1999) CA – 0.86	Low peer and supervisor support was associated with low job satisfaction. No interaction effects between job demands, and support were found for job satisfaction.	Only three items of the sub-scale of the LQWQ were used, therefore several facets of job satisfaction would have been missed. Random sampling was used, but the data analysed was collected from a previous study thus limiting generalisability. The authors did not account for or acknowledge potential differences between types of setting.
Willemse <i>et al.</i> (2015) Holland	To explore the relationship between person centred care and job related wellbeing.	Cross sectional (Data collected from a previous study). Multilevel linear regression analysis.	Nurses and nursing assistants N = 1093 Mean age- 43.2 Gender %- Not detailed	Range of settings including nursing homes, care homes and specialised dementia units.	Job Satisfaction subscale of the Leiden Quality of Work Questionnaire (van der Doef & Maes, 1999) CA – 0.86	High job satisfaction had a positive relationship with person centred care and a negative relationship with emotional exhaustion.	Random sampling was used, but the data analysed was collected from a study completed four years previously. Only three items of the sub-scale of the LQWQ were used, therefore several facets of job satisfaction would have been missed. The authors did not account for or acknowledge potential differences between types of setting.

Appendix E – Summary of reviewed studies(Continued).

Author(S)/Year/ Location	Aim of the study	Study design Analysis of job satisfaction variable	Sample	Setting type	Job satisfaction measure Author Chronbach's alpha (CA)	Notable findings	Limitations
Zimmerman <i>et al.</i> (2005) USA	To explore the relationship between stress, attitudes and job satisfaction.	Cross Sectional. Multiple linear regression analyses.	Direct care workers N = 154 Mean age- 39.9 Gender %- Female 93.5 Male 6.5	Nursing homes and residential care assisted living.	Staff Experience Working with Demented Residents. (Astrom <i>et al.</i> 1991) CA – Not reported	A person centred attitude, perceived competence and lower levels of stress were associated with higher levels of job satisfaction.	The study defined stress, but not attitude or job satisfaction. Participants had to provide information about residents they were familiar with, this may have biased their responses on the attitudes, stress, and satisfaction scales.

Appendix F – Researcher context

This account describes the researcher's position to aid transparency of the co-construction of the account between himself and the caregivers. The researcher worked for 12 months on a specialist dementia and challenging behaviour unit as an Assistant Psychologist. The unit offered a secure care pathway to service users primarily over 55 years of age, who had challenging behaviour (including ISB) as a consequence of either early onset, acquired, static or progressive dementia. The researcher has himself experienced ISB such as verbal comments and touch and has also supported staff who have experienced ISB to varying degrees of severity. He has witnessed distress caused by ISB in staff, other residents and family members; therefore, was aware that this research may illicit feelings of distress in potential participants. Furthermore, prior to and during the research the author held the view that the intention behind an observed behaviour may not always be sexual in nature rather that an individual may be trying to communicate other needs. This stems from his experience in the management of challenging behaviour such as ISB which required formulating why it may be occurring in the first instance. The researcher is aware that his perception of what constitutes ISB gained through experiences of working in an inpatient setting is likely to be different to the meanings and interpretations given by family caregivers living at home with someone who displays such behaviour. Thus, the researcher acknowledges that there will be an inherent subjective interpretation of caregiver accounts as his own experiences will guide his sense making of their narratives.

Appendix G – Epistemological position

The epistemological position of the researcher is that of a critical realist.

A social constructionist position argues that which we perceive is not a direct representation of the environment; instead the creation of knowledge derives from social, historical and cultural factors (Gergen, 1985). Alternatively, positivism emphasises that knowledge claims are a result of scientific empirical methods which implies the existence of an objective outside observer (Cruikshank, 2012). Thus, a constructionist approach is more interested in the subjective experience of the individual whilst a positivist approach focuses on behaviour which can easily be observed and measured. Bearing in mind the methodological approach to the current study, Smith *et al.* (2009) describe IPA as sitting in between the two positions; a critical realist stance.

Bhaskar's (1975/1977) critical realist theory (as cited in Cruikshank, 2012) contends that social structures arise from individual actions. Whilst a critical realist gains knowledge from observations grounded in reality, it is accepted that this reality may be different for each person observing the same phenomenon (O'Gorman and Macintosh, 2015). Furthermore, the authors propose that our interpretation of reality is influenced by our own perceptions. ISB is an interesting concept, there is an observable behaviour which does exist and can be measured for example, by its frequency or severity (Knight *et al.* 2008). However as has been previously discussed, this behaviour, shaped by society, can be interpreted in many ways and there is no one fixed truth as to what it means (Tsatali *et al.* 2011). Whilst people will observe this particular behaviour, the meaning they ascribe to it may be influenced by their own experiences, culture and values. Given the nature of ISB, positivist and constructionist approaches are not mutually exclusive. Critical realism seems to capture both the reality of the observed physical behaviour and the interpretation of the person experiencing it.

Appendix H – Letters from the ethics committee



Health Research Authority

24 February 2015

Mr Andrew Stranaghan
University of Leicester, Clinical Psychology
104 Regent Road
Leicester
LE1 7L1

Dear Mr Stranaghan

Study title:	Inappropriate Sexual Behaviour in dementia: The lived experience of the caregiver
REC reference:	15/EM/0040
Protocol number:	4
IRAS project ID:	167787

Thank you for your submission of 23 February 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the Acting REC Manager, [REDACTED]

[REDACTED] Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see

"Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Interview schedules or topic guides for participants [Topic guide]	4	02 December 2014
IRAS Checklist XML [Checklist_05012015]		05 January 2015
Other [Participant Opt in form]	1	02 December 2014
Other [Demographic information sheet]	2	02 December 2014
Other [Supervisor CV summary (2)]	1	01 September 2014
Participant consent form [Participant Consent Form]	4	02 December 2014
Participant information sheet (PIS) [Participant Information Sheet]	5	20 February 2015
REC Application Form [REC_Form_05012015]		05 January 2015
Research protocol or project proposal [Research protocol]	4	02 December 2014
Summary CV for Chief Investigator (CI) [CI CV]	1	05 December 2014
Summary CV for supervisor (student research) [Supervisor CV Summary (1)]	1	22 December 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form

available on the HRA website:
<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

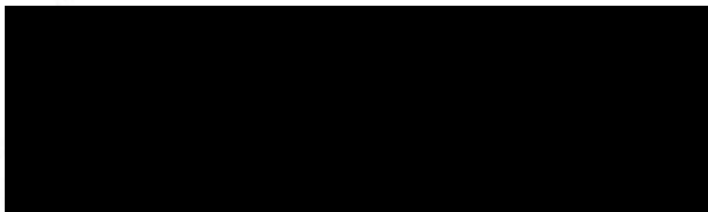
We are pleased to welcome researchers and R&D staff at our training days – see details at
<http://www.hra.nhs.uk/hra-training/>

15/EM/0040

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



Enclosures: "After ethical review – guidance for researchers"

Copy to:



Appendix H – Letters from the ethics committee (Continued)



16 November 2015

Mr Andrew Stranaghan
University of Leicester, Clinical Psychology
104 Regent Road
Leicester
LE1 7LT

Dear Mr Stranaghan

Study title:	Inappropriate Sexual Behaviour in dementia: The lived experience of the caregiver
REC reference:	15/EM/0040
Protocol number:	4
IRAS project ID:	167787

Thank you for your letter of 02 November 2015, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

Document	Version	Date
Notice of Minor Amendment [Addition of new sites]		02 November 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

15/EM/0040:	Please quote this number on all correspondence
-------------	--

Yours sincerely

[Redacted signature block]

Copy to:

[Redacted list of recipients]

Appendix H – Letters from the ethics committee (Continued)



12 February 2016

Mr Andrew Stranaghan
University of Leicester, Clinical Psychology
104 Regent Road
Leicester
LE1 7LT

Dear Mr Stranaghan,

Study title:	Inappropriate Sexual Behaviour in dementia: The lived experience of the caregiver
REC reference:	15/EM/0040
Protocol number:	4
Amendment number:	04/02/2016
Amendment date:	04 February 2016
IRAS project ID:	167787

Thank you for your letter of 04 February 2016, notifying the Committee of the above amendment.

The Committee does not consider this to be a 'substantial amendment' as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

Document	Version	Date
Notice of Minor Amendment (email)	04/02/2016	04 February 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

15/EM/0040:	Please quote this number on all correspondence
-------------	--

Yours sincerely,

[Redacted signature]

Copy to:

[Redacted recipient list]

Appendix I – Topic guide



Introduction

How is a typical day for you as a caregiver?

Prompts

- *Most/least challenging aspects*

Experience

You have come to talk about ISB. Can you tell me about your own experience(s) of this?

Prompts

- *What, when and where*
- *Emotional reaction – How it made you feel*
- *Your sense/meaning of this*
- *Is it something you've experienced before?*
- *Comparison to other challenging behaviours you have experienced*

Living with

How is it living with someone who presents with this type of behaviour?

Prompts

- *Impact on your day to day life*
- *How has it affected your relationship with the person*

Nature of ISB

How does this behaviour make you think/feel about your relative?

Prompts

- *Most/least challenging aspects of the behaviour*
- *How do you think others view you or your relative*
- *Impact on others – Family/Friends*
- *Why would you consider this behaviour to be sexually inappropriate?*

Responding

What do you do when this behaviour occurs?

Prompts

- *Managing the behaviour – What has been helpful/unhelpful*

Support

What support, if any, do you feel you need with this behaviour?

Prompts

- *Have you had any support*
- *Are you able to discuss this behaviour with others – family/friends/professionals*

Closing

Are there any aspects of your experience(s) of ISB that we have not discussed?

Participant information sheet

Inappropriate Sexual Behaviour and dementia: The lived experiences of caregivers.

You have been invited to take part in a research study. The following information has been provided to give you an understanding of why the study is being done and what it will involve. Before you decide whether or not you would like to take part, please take time to read this information carefully.

What is the purpose of the study?

This study aims to interview family caregivers of people with dementia. The study will explore caregivers' experiences of Inappropriate Sexual Behaviour (ISB) as displayed by the person they are caring for. The aim is to gain a better understanding of this behaviour and its impact on the life of a caregiver. ISB has been described as a physical or verbal act of sexual nature which may be considered inappropriate within the social context it occurs.

Why have I been invited to participate?

Participants for this study were identified through *** and ***. Family caregivers of individuals with dementia known by these services have been invited to take part.

Do I have to take part?

Taking part in this study is entirely voluntary; it is up to you whether or not you decide to take part. If you decide to take part, you are free to withdraw from the study at any time without giving a reason. A decision to not take part or withdraw will not affect the care of you or your family member.

What will happen to me if I take part?

If you decide to take part in the study please complete the attached 'opt in' form and return it in the stamped addressed envelope. The lead researcher will then contact you and arrange to meet you in order to complete an interview. If you choose to, the researcher will arrange an initial meeting with you to discuss the project.

The interview will take place at your home, unless you would like to identify a more suitable location. If the interview is conducted at your home, it will not be conducted in the presence of the person you are caring for. If this is not possible, the interview will be stopped if the person you care for begins to exhibit distress.

The interview should last approximately between one and two hours. Only one interview will be required, but if it is not possible to complete it in one appointment the researcher will arrange to meet you again if that is acceptable to you. Breaks can be taken at any time through the interview.

The aim is to give you an opportunity to talk openly about your experiences. It is hoped the interview will be more like a conversation about your experiences rather than a formal question and answer session. There will be an opportunity after the interview to discuss any questions or concerns that you may have.

What are the possible benefits of taking part?

It is hoped that this study will help you by giving you the opportunity to discuss your experiences of ISB whilst caring for your relative. The researchers hope that the findings from this study will help develop a better understanding of what is like to live with and care for someone who displays ISB.

What are the potential risks?

The potential risks of participation are minimal. However, talking about your experiences may evoke a range of emotions. Breaks can be asked for throughout the interview if it causes you distress. The researcher will offer the opportunity to discuss this after the interview and provide information on support services should you find the process distressing. Additionally, if you do have any worries or concerns and would like to get in touch with an independent service, the *** Patient Advice and Liaison Service (PALS) can be contacted via telephone on ***. Further details of this service can be provided after the interview.

Will my participation in this study be kept confidential?

Yes. Any information provided by you for the study will be anonymous and confidential.

There may be times during the analysis when others involved in the study will read the written material from the interviews, but they will not have access to your personal information and will not be able to identify you. All written material will be kept in lockable box when not being analysed. Any information kept on a computer will be password protected and destroyed five years following the study. Some quotations may be used in the final report and publication of the study. However, these will be anonymised and you will not be identifiable.

Information will only be shared outside of the research team in circumstances where there is considered to be serious risk to yourself or others. In these instances, the researcher will inform the relevant service (*** or ***) of the potential risk. Wherever possible you will be informed of this information being shared.

What will happen to the results of the study?

The results of the study will form the researcher's doctoral thesis and is expected to be published in a peer-reviewed journal. A copy of results will be sent to services involved in the research and findings will also be shared with peers at the University of Leicester. If any participants wish to receive a report about the study's findings they can inform the researcher at time of the interview. Other dementia services interested in the findings may also be provided with a report.

Has the study been approved?

Yes. This study has been approved by the University of Leicester and the National Research Ethics Service Committee ***, an NHS ethics committee.

Contact for further information

If you have any questions or would like more information please contact the researcher in the first instance or project supervisors on the following numbers:

Andrew Stranaghan, Trainee Clinical Psychologist (Researcher) - ***
Noelle Robertson, Clinical Psychologist (Supervisor) - ***
Sheila Bonas, Clinical Psychologist (Supervisor) - ***

Thank you for taking the time to read this information sheet.

Appendix K – ‘Opt-in’ form



Opt in form

Title of study: ‘Inappropriate Sexual Behaviour and Dementia: The lived experience of caregivers.’

Study lead: Andrew Stranaghan, Trainee Clinical Psychologist, University of Leicester.

I confirm that I have read and understood the participant information sheet and am interested in taking part in the research.

I am happy to for you to contact me so that we can discuss the study.

My contact details are:

Name:

Telephone number:

My preferred contact times are:

Name: _____

Signature: _____

Date: _____

Please return this form in the enclosed stamped addressed envelope.

Thank you.

Appendix L – Consent form

Consent form



'Inappropriate Sexual Behaviour and dementia: The lived experiences of caregivers.'

Andrew Stranaghan, Trainee Clinical Psychologist, University of Leicester

Please read and complete this form carefully. If you do not understand anything and would like more information, please ask.

Please
initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, and that my or my relatives future care will not be affected in any way. ☐
3. I agree to the interview being audio recorded as part of this research project. ☐
4. I understand that any audiotape material of me will be used solely for research purposes and that anonymised quotations may be used in the final write up and publication of the study. ☐
5. I understand that audio tapes will be stored securely and will only be listened to by specified people involved in this research study. ☐
6. I understand that all information about me will be treated in strict confidence, I will not be named in any written work arising from this study and all research data will be destroyed after five years. ☐
7. I understand that the risk in this study is that through speaking about my experiences I may become upset or distressed and that I can ask for a break from or termination of the interview at any time. ☐
8. I agree to take part in the above study and understand the nature of the research project and of what will be expected of me ☐

Name of Participant (Block Capitals)

Date

Signature

Name of Researcher (Block capitals)

Date

Signature

Appendix M – Transcript example

		Initial comments	Emerging Themes
412	you don't keep talking about it, you, you have to let things like be	feelings are not sure	How relationship is now
413	natural, there's feelings there, things will happen". But he can't grasp	He doesn't understand	Impact of behaviour
414	that what he's doing is, is actually(.)putting me off him(.)a lot. Then	Behaviour putting me off	on me
415	you feel guilty because you are his wife.	Guilt - I am his wife	Expectations wife/relationship
416			
417	(26.28) I: Can you tell me a little bit more about that, about feeling		
418	guilty because you are his wife.		
419			
420	A: Because erm(.)well when your husband and wife, you are supposed	Supposed - Assumption /	Expectations wife/
421	to participate in all of these things, and it's as if I'm refusing him or	belief	relationship
422	avoiding, which I am. Because it's not him whose making these	I'm not willing to do this	Out of his control
423	remarks, I, it's, it's like somebody's took over, somethings took over	It's not my husband	We are strangers
424	him, and he's not looking at me as his wife because there aint the	He has been taken over	
425	respect there. Not when- -the way he talks, there's no- -it's not	He sees someone different	
426	respectful.	in me	
427			
428	I: How does that make you feel in the relationship?		
429			
430	A: I get very fed up with it, erm(.)sometimes I'm glad if he went off to	I've had enough	"An animal waiting
431	bed, so I get a bit of peace. But then- -but now, it's it's- -he is like	Peace - without conflict	to attack"
432	waiting for me. It's like erm(.)it's like an animal waiting to attack if you	Metaphor - "Animal waiting	(Relentless / fear)
433	understand what I mean.	to attack"	
		(Predator/prey??)	

*Appendix N – Theme development** (Table 3)

Text	Initial coding	Emergent theme	Subordinate theme	Super-ordinate theme
“A: Yeah, 'cos like(.)my sister used to see some of how he acted at times. Erm(.)but, it's always different looking from the outside in, but it's like, they are only there for a short time...”	Difference ‘looking in’. Others only around for a short time. They can leave.	Different from the outside.	“Outsiders” (Anne)	Making sense of “outsiders”
“So I don’t think(.)again I think its lack of understanding. Definitely(.)until you actually go through it, I probably wouldn’t have understood a lot of it, the inappropriate sexual behaviour.”	Can only understand a situation when you experience it.	You have to live the experience.		
“...‘cos people seem to avoid when you got somebody(.)there aren’t many friends come.”	Friends don’t visit. Limited social contact.	Abandonment	“You have to sort of put up with it by yourself” (Anne)	
“It is, erm, but I think it does good to talk about it otherwise you bottle it up. Erm(.)but a lot of my people are eighties or nineties and you don’t talk to people about things like that.”	It is good to talk. ISB is not something you talk to other people about. Age? Older people don’t talk about it?	Can’t talk about ISB		

*N.B. This table is not comprehensive as it demonstrates some examples of data at each stage of analysis.

Appendix N (Continued) – Theme development

Text	Initial coding	Emergent theme	Subordinate theme	Super-ordinate theme
“Yeah, yeah, He just can't, you know, and, and, he just don't want to think about it.”	Son does not want to think about the behaviour. Not acknowledging.	“It's a mother son thing”	“Mum, you can't do that” (Michael)	Making sense of “outsiders”
“My daughter understands and she says 'oh, come on Mum, you can't do that', you know 'what's the problem' sort of thing, you know or 'how can I help you'. Erm, but my son would be mortified...”	Difference between how son and daughter experience the behaviour.	Difference in my children.		
“So they are just used to it, you know, erm we have got- -boiled ourselves down to a circle of friends, an awful lot of friends that we saw, we don't see any more for obvious reasons, erm, erm, but we have still got that close circle of local friends that are just used to it, you know.”	'Boiled ourselves down'. Smaller social network. Friends are familiar with the situation.	Friends know and understand the behaviour.	Friends understand and strangers misconstrue. (Michael)	
“...she'd erm go- -she'd sort of takes her clothes off as I say erm(.)at inopportune moments and I think this would be construed as being sexual and it wasn't really ...”	Others could construe this behaviour as sexual. Michael didn't think so. It could happen out in public.	Strangers misconstruing.		

*N.B. This table is not comprehensive as it demonstrates some examples of data at each stage of analysis.

Appendix O – Methodological rigour

Elliott *et al.* (1999) suggested guidelines to aid the quality of qualitative research, these included: owning one's perspective (such as describing personal experiences related to the researched topic), grounding in examples (providing extracts of data to support themes) and credibility checks (asking others to look over the analysis). The quality of the current research was enhanced through various means. The researcher attended an IPA training course to develop their knowledge of the methodology and to build skills in its practical application from interviewing through to analysis. Data analysis such as coding and emerging themes was discussed with academic and field supervisors to support credibility. Furthermore, the researcher attended a regular qualitative supervision group with peers who were also conducting qualitative based studies. As part of this group the researcher had discussions regarding the coding of their own and others transcripts. As the interpretations of the researcher is important in IPA (Smith and Osborne, 2003) a diary to aid reflexivity was kept throughout the project. This allowed the researcher to note reflections, questions, issues and solutions. The diary was used to develop the critical appraisal section of this report.

Appendix P – Research Chronology

February 2014

- Confirmation of research supervisors.

February – May 2014

- Consultation with supervisors to finalise thesis topic.

May 2014

- Research proposal submitted for internal peer review at the University of Leicester.

October 2014 – January 2015

- Preparation for ethics submission (Completing application form and talking to caregivers to gain feedback).
- Preparation for submission to Research and Development.
- Submission of proposal for Service User Reference Group (SURG) review.

January 2015

- Attended ethics review meeting.

February 2015

- Favourable opinion received from ethics committee.
- Approval received from Research and Development.

March 2015

- Attended one day IPA training course.

May 2015 – March 2016

- Development and write up of literature review.

July 2015

- Pilot interviews with staff members based within a neuropsychiatry service.

July 2015 – March 2016

- Recruitment of participants.

November 2015 – January 2016

- Interviews carried out.

November 2016 – March 2016

- Interview transcription and data analysis.

December 2015 – April 2016

- Thesis write up.

April 2016

- Two-week extension granted.

May 2016

- Thesis submitted to the University of Leicester.

September 2016 onwards

- Planned dissemination.