

Men caring for wives/partners with dementia

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Men caring for wives/partners with dementia: masculinity, strain and gain.

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Thesis Abstract

As the demographics of the population change, men are becoming increasingly important as caregivers. In the U.K., as in many countries, there are equal numbers of men and women caring for someone in their own home. Research comparing men with women carers has described sex differences in caregiving. However, these differences do not describe the variation across different men. Improving interventions and support for men would need to be informed by the ways in which men respond to the strains of caregiving.

A systematic literature search was carried out to determine what is known about men coping with caring for someone with dementia. There is some interest in the different responses to carer burden from each sex, but no studies were found that assessed gender as a possible mediating factor between coping and burden. Very few studies had focused on men, or had attempted to describe the variation of responses within male carers. The problems of assessing individual differences, response bias and operationalising coping are discussed.

A questionnaire survey of seventy men caring for their wife or partner with dementia was carried out to assess whether gender identity and gender role conflict are important factors in the men's appraisals of strain and gain about their caregiver role. Gender identity, as operationalised by the Personal Attributes Questionnaire, was found not to contribute significantly to appraisals of strain and gain in comparison to established measures such as self-rated health, duration of caregiving and the carer's reaction to memory and behaviour problems. In contrast, aspects of the Gender Role Conflict Scale, representing traditional beliefs about masculinity, significantly contributed to regression models of appraisals of strain and gain. The implications for this in terms of further research and clinical practice are discussed.

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Table of Contents

Thesis Abstract.....	ii
Acknowledgements.....	iii
Word counts.....	iv
Table of Contents.....	1
List of Tables.....	5
List of Figures.....	7
1.0 Literature Review: Men coping with caring for someone with dementia.....	8
Abstract.....	9
1.1 Introduction.....	10
1.2 Systematic literature search.....	13
1.2.1 Method.....	13
1.3 Findings of the literature search.....	14
1.3.1 Studies reporting gender differences.....	15
1.3.2 Studies reporting no gender differences.....	17
1.3.3 Studies focusing exclusively on men.....	18
1.4 Discussion.....	26
1.4.1 Addressing individual differences.....	26
1.4.2 Operationalising coping.....	27
1.4.3 Self-report bias.....	28
1.5 Conclusions and Implications for further research.....	29
1.6 References.....	31
2.0 Research Report: Men caring for wives or partners with dementia: Masculinity, strain and gain.....	38
Abstract.....	39
2.1 Introduction.....	40

2.1.2 Gender differences.....	41
2.1.3 Research on husband caregivers.....	43
2.1.4 Gender identity and gender role conflict.....	45
2.1.5 Research question and hypotheses.....	48
2.2 Method Section.....	50
2.2.1 Design.....	50
2.2.2 Participants.....	50
2.2.3 Measures.....	51
2.2.4 Research Procedure.....	55
2.2.5 Ethical Approval.....	57
2.3 Results.....	58
2.3.1 Descriptive data.....	58
2.3.2 Reliability of the Measures.....	60
2.3.3 Inter-correlations of variables.....	61
2.3.4 Hypothesis 1.....	63
2.3.5 Hypothesis 2.....	65
2.3.6 Hypothesis 3.....	67
2.4 Discussion.....	70
2.4.1 Gender Identity.....	70
2.4.2 Gender Role Conflict.....	71
2.4.3 Possible explanations for the findings.....	73
2.4.4 Clinical Implications.....	76
2.4.5 The limitations of the study	77
2.4.6 Future Research.....	78
2.4.7 Conclusion.....	79
2.5 References.....	80
3.0 Critical Reflection.....	90
3.1 Origins of the study.....	91
3.2 Development of the study.....	93

3.3 Data collection.....	95
3.4 Feeding back.....	96
3.5 Writing up.....	97
3.6 Critique of the research.....	98
3.7 Summary: Reflecting on the whole.....	100
3.8 References.....	102

List of Appendices

Appendices.....	104
Appendix 1: Instructions to authors: The Gerontologist, Aging and Mental Health.....	105
Appendix 2: Explanation of why a coping measure was not used.....	110
References.....	112
Appendix 3: Contact letters to colleagues and potential participants, contact form and information sheet given to potential participants.....	113
Appendix 4: Questionnaire, participant introduction letter, and consent form.....	119
Appendix 5: Ethics committee approval letter.....	130
Appendix 6: Breakdown of number and type of services used.....	133
Appendix 7: Comparison of the internet-recruited sample and the locally-recruited sample.	134
Appendix 8: Inter-correlation matrix between all variables used in the study.....	137
Observations on the correlation matrix: Strain.....	137
Observations on the Correlation Matrix: Gain.....	139
Observations on the correlation matrix: Gender Identity.....	139
Observations of the correlation matrix: Gender Role Conflict.....	139
Appendix 9: Hierarchical regression statistics for the three dependent variables: Including measures to assess normal distribution of residuals, Cook's D for outliers, residual scatterplots for homoscedascity and linearity, and measures of collinearity.....	141
References.....	146
Appendix 10: ANOVA tables comparing median-split PAQ groups.....	147
References.....	149
Appendix 11: The Gender Role Conflict Scale.....	151
Description of the Gender Role Conflict Scale.....	151
GRC and older men.....	152
Conclusion.....	153
References.....	153

List of Tables

Table 1: Categories and corresponding number of articles resulting from the literature search focused on the coping of male caregivers of people with dementia.....	15
Table 2: Articles reporting research and interventions focused on men caregivers of dementia addressing coping in respect of caregiver problems.....	20
Table 3: Description of the contents of the questionnaire.....	51
Table 4: The constructs, original item numbers and factor loadings from the Gender Role Conflict Scale (O'Neil, et al., 1986) used in the adapted GRCS in the present study	54
Table 5: Recruitment protocol used in the study.....	56
Table 6: Demographic variables describing the sample (N = 70).....	58
Table 7: Frequency breakdown of number of helpers and services used (N = 70).....	58
Table 8: Frequency breakdown of years of education (N = 70).....	59
Table 9: Frequency breakdown of self-rating of health (N = 70).....	59
Table 10: Cronbach alphas of the scales used.....	60
Table 11 : Intercorrelations of Independent and Dependent variables used in the regression analyses (N = 70).....	62
Table 12: Hierarchical multiple regression predicting Role Strain among husband caregivers (N = 68).....	64
Table 13: Hierarchical multiple regression predicting Personal Strain among husband caregivers (N = 69).....	66
Table 14: Hierarchical multiple regression predicting Gain among husband caregivers (N = 69).....	68
Table 15: Breakdown of type of service used by the participants and their frequency.....	133
Table 16: Frequency breakdown of geographic location of internet sample (N = 33).....	134

Table 17: Comparison of demographic, predictor and outcome variables for the two samples used in the study.....	135
Table 18: Standardised residuals statistics for the independent and dependent variables used in each hierarchical regression analysis.....	141
Table 19: Colinearity statistics for the Role Strain independent variables.....	145
Table 20: Colinearity statistics for the Personal Strain independent variables.....	145
Table 21: Colinearity statistics for the Gain independent variables.....	146
Table 22: Means (SDs) of the dependent variables for the participants grouped into androgynous, high masculine, high feminine and undifferentiated using median splits on their PAQ-F/Expressive and PAQ-M/Instrumentality scores.....	148
Table 23: Analysis of variance of Role Strain between the four PAQ median-split groups.	149
Table 24: Analysis of variance of Personal Strain between the four PAQ median-split groups.....	149
Table 25: Analysis of variance of Gain between the four PAQ median-split groups.....	149

List of Figures

Figure 1: Schematic diagram of the research design showing the variables concerned.....	50
Figure 2: Model of how men caring for their wives/partners with dementia, may appraise role Strain, Personal Strain and Gain as a consequence of a socially desirable response bias related to their beliefs about masculinity.	75
Figure 3: Box-plot of Cook's D for the IVs and DV of the Role Strain regression to determine outliers. Two participants' data (numbers 2 & 12) was excluded from the final hierarchical regression analysis.....	142
Figure 4: Box-plot of Cook's D for the IVs and DV of the Personal Strain regression to determine outliers. One participant's data (number 7) was excluded from the final hierarchical regression analysis.....	142
Figure 5: Box-plot of Cook's D for the IVs and DV of the Gain regression to determine outliers. One participant's data (number 33) was excluded from the final hierarchical regression analysis.....	143

1.0 Literature Review: Men coping with caring for someone with dementia.

Men coping with caring for someone with dementia.

Kevin L. Baker

Abstract

As the demographics of the population change, men are becoming increasingly important as caregivers. However, caregiving is often portrayed as a feminine activity and there is a need for more research focusing on men carers. Research comparing men with women carers has described sex differences in caregiving and outcome measures. However, these differences do not describe the variation within men. Improving interventions and support for men would need to be knowledgeable about the ways in which men cope with the strains of caregiving. To this end, a systematic literature search was carried out to determine what is known about men coping with caring for someone with dementia.

The search resulted in 91 articles that were reviewed and categorised by their content. The majority of articles reported on research and interventions without any detailed analysis of gender as a mediating variable for coping. Some articles reported sex differences, but again did not investigate variations of coping within the sexes. Four articles reported finding no sex-differences in coping and burden. Of the nine articles that reported exclusively on men caregivers, only one used a quantitative approach and a theoretical framework of stress, appraisal and coping.

A review of the literature suggests that there is a need for further sophistication to address how gender may mediate appraisals of strain and coping responses to familial dementia care. The limitations of gender difference research and self-report methodologies are discussed along with their implications for interventions and suggestions for future research.

Key words: dementia care, male caregiver, burden, coping.

Target Journal: The Gerontologist.

1.1 Introduction

Caring has traditionally been described as a woman's activity, and in general, women are more likely to take on caring roles than men (Office for National Statistics, 2002). However, as demographic changes have transformed the constituency of many Western societies, many more men have adopted caring roles (Kaye & Applegate, 1990). For example, in the U.K., men are just as likely as women to be caring for someone in their own home (Office for National Statistics, 2002). In the older age groups over 65, men are in fact more likely than women to be caring for their spouse (Office for National Statistics, 2004). Concomitant with the aging of the population are the rising numbers of people suffering from a dementia. Dementia caregiving places particular demands on the carer due to the progressive nature of the disease and involves the carer adapting their relationship to the care-recipient (Zarit & Edwards, 1999). Compared to caregiving in general, dementia care is likely to involve an increase in the number of hours care per week, an increase in strain and consequent physical and mental health problems (Baumgarten et al., 1992), complications with the caregiver's career, reduced leisure time, and an increase in family conflict (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999).

Increasingly researchers have remarked that the literature on caregiving of the elderly has assumed that the predominant caregiver is female (Horowitz, 1985; Kaye & Applegate, 1990; Kramer, 2000; Zarit, Todd & Zarit, 1986), and have remarked on the paucity of research about men caregivers (Gregory, Peters & Cameron, 1990; Kaye & Applegate, 1990; Kramer, 2000). It has long been known that there are gender differences in the reported burden of caregivers of dementia patients (Barusch & Spaid, 1989; Zarit & Edwards, 1999), but there have been few studies investigating this in detail. The little that is known suggests that older husband caregivers report spending more hours giving care than other caregiver groups (Chang & White-Means, 1991; Office for National Statistics, 2005; Stone Cafferata, & Sangl, 1987), and over half report receiving no help from others (Stone et al., 1987).

Strain and Blandford (1999) reported that male caregivers are significantly less likely to be aware of the availability of community services than female caregivers, and this may underpin the reduced access and low use of services (Toseland et al., 1999). In addition, people's beliefs about themselves and attitudes to services are influential. Stommel, Collins, Given and Given (1999) reported that in comparison to women caregivers, men are more concerned about the opinions of others, more inclined to prefer family independence in providing care, more likely to reject government provision of community services, and less confident in those same services.

Kaye and Applegate's (1993) survey of caregiver support-group facilitators reported that the most common factor preventing men from participating was that they held the attitude that men should be able to manage caregiving without help. An appreciation of male gender role socialisation can help understand this 'masculine' stoical attitude to care, where attending a support group can potentially contribute to men's perceptions of themselves as weak, as a failed carer, and losing control. However, Kaye and Applegate (1993) found that once men had joined a support group, their level of attendance was equivalent to that of the women members.

Interventions and support services for caregivers have examined theories and models of coping to help inform more effective strategies. Lazarus and Folkman's (1984) model of stress-appraisal coping has had prominence, particularly since being adapted for dementia-care (e.g. Pearlin, Mullan, Semple & Skaff, 1990). Using coping theory, applied researchers have investigated the relationship between the level of stress experienced by carers and coping styles and behaviours. Gender has often been used as a demographic independent variable in these studies with men being reported as using instrumental or problem-focused coping, and women using more emotion-focused coping strategies (e.g. DeVries, Hamilton, Lovett & Gallagher-Thompson, 1997; Garity, 1997; Hooker et al., 2000; Lutzky & Knight, 1994). However, there has rarely been any further analysis of how gender operates as a mediating variable between coping and burden.

Matson (1994) has noted that coping may vary for different carers and client groups, and that interventions should not adopt a blanket approach by focusing on any single factor of coping. Kneebone and Martin (2003) re-emphasised this when suggesting, in their review of coping in community- and family-situated dementia care, that more specificity in the research is required to effectively inform interventions, and that research needs to identify coping efficacy in various contexts and target interventions in response to individual needs.

Although there has been some acknowledgement in the caregiving literature that coping with caregiving is not uniform, and that various meanings are ascribed to the caregiving experience (Archer & MacLean, 1993; Haley, Levine, Brown, Berry & Hughes, 1987), the majority of research has continued to ignore individual differences (Vitaliano, Scanlan & Zhang, 2003). Thus, Kneebone and Martin (2003) have concluded that much of the literature on dementia caregiving is limited in its ability to inform the clinician about any effective intervention.

It is not surprising then, that the evaluation of interventions, such as those teaching coping strategies to carers of older confused people, have reported mixed results (Carradice, Beail, & Shankland, 2003; Matson, 1994). Several authors have commented that adaptive coping skills need to be carefully considered and delivered with specific acknowledgement of the carer's context, the type of person being cared for, and the nature of the stressors at the time of delivery (Kneebone & Martin, 2003; Matson, 1994; Williamson & Schulz, 1993). Carradice, Beail, and Shankland (2003) criticised the literature evaluating interventions for dementia caregivers for poor methodological rigour and suggested that clearer evidence for efficacy could be gained from using more theoretically-driven interventions and research design.

Carradice et al.'s (2003) focus on theoretically-driven practice does not mean that practitioners need to feel lost in designing interventions. Ferris and Mittelman (1996) described an intervention study to help caregivers cope with caregiving to a husband or

wife with Alzheimer's disease, and to delay nursing home placement. The intervention appeared to be successful in that, although the general elements of the programme were quite broadly specified, the intervention was tailored to the specific needs of each caregiver. Thus, the intervention was long-term, continuous and adaptive to the individual. Results revealed that the intervention delayed nursing home placement and relieved caregivers from depressive symptomatology, an outcome shown to be possible in other successful interventions (Brodaty, Green & Koshera, 2003).

In summary, given that the majority of older caregivers are men, and that men are reluctant to use services, developing and improving support for them is an important aim. However, before services can be developed to better enhance support for male carers, knowledge of how men cope with caring for someone with dementia is needed. A systematic search of the literature was therefore undertaken to evaluate the current knowledge about men's coping with the role of dementia caregiver.

1.2 Systematic literature search

1.2.1 Method

A systematic literature search was conducted on the following computerised databases: Medline (1950 to April 2006), PsychInfo (1906 to April 2006); British Nursing Index (1994 to April 2006), CINAHL (1982 to April 2006), and SocialSci Search (1972 to April 2006). The titles and abstracts were searched using the terms "Alzheimer OR dementia", "caregiving OR caregiver(s) OR carer(s)", "coping", and "men OR male OR spouse(s) OR spousal OR husband(s) OR son(s) OR gender". These four searches were combined with the AND operator to identify the research literature on caregiver coping with dementia involving men. The Med-Line database yielded 54 references, the PsychInfo database 108, the British Nursing Index 3, CINAHL 54, and the SocialSci Search 53.

After deleting duplicates, the search resulted in 154 research articles. Exclusion criteria were applied to omit dissertations, book chapters, studies that focused on

interventions for patients and not caregivers, women caregivers with no mention of men caregivers, and studies with only incidental mentions of coping and gender. This resulted in seventy articles being discarded. Next the references to each paper were scanned for further possible research articles that may be relevant to the literature search. This resulted in an additional seven papers that focused on coping in male caregivers, bringing the final result of the search to 91 articles.

1.3 Findings of the literature search

The research articles were read through and discussed with two clinicians knowledgeable about the area of dementia care. Categories were developed that best described the aims and findings of the articles, and each article was allocated to a category after full agreement was reached about its content. The categories and numbers of articles allocated to them, are displayed in Table 1 below.

The aim of the search was to review the coping of men caring for someone with dementia. The articles in Categories A and B (Table 1) did not consider any analysis in terms of gender and so were not useful in furthering this aim. However, before dismissing them, some comment is necessary as they formed the majority of the articles in the search.

In total, sixty articles, were identified in the search primarily because they described men, women and/or spouse participants in studies or interventions focused on coping in dementia caregiving. In these articles, participants were often described as spouses with no differentiation made between husbands and wives. Frequently, despite the sex of the participants being recorded, there was no further analysis to consider variation and differences that may be caused or mediated by gender. This lack of specificity suggests Kaye and Applegate's (1990) assertion that gender is not considered an important factor in caregiver research, is still true. A consequence of this is that the gendered nature of caregiving is essentially unquestioned and therefore hidden (Hooyman & Gonyea, 1995). In these studies the term 'caregiver' can be interpreted to mean anyone from husband to

daughter-in-law and hides potentially useful information about variations of response to caregiver burden.

Table 1: Categories and corresponding number of articles resulting from the literature search focused on the coping of male caregivers of people with dementia.

Category	Number of Articles
A) Articles reporting on research designed to investigate caregiver burden and/or coping, but did not report an analysis in terms of gender	51
B) Articles reporting on interventions with no analysis in terms of gender	9
C) Articles reporting research designed to investigate gender differences in burden and/or coping that reported gender differences	9
D) Articles reporting research designed to investigate caregiver burden and/or coping in general, and reported gender differences as a consequence of their findings	9
E) Articles reporting research designed to investigate caregiver burden and/or coping, and reported finding no gender differences	4
F) Articles reporting research and interventions focused on men only	9
Total	91

The remaining articles from the literature search can be broadly grouped under the headings of those reporting gender differences, those reporting no gender differences, and those focusing on men only. These will be described respectively below.

1.3.1 Studies reporting gender differences (Categories C and D, Table 1)

Eighteen papers reported gender differences in coping with dementia caregiving. Nine studies (Category C) explicitly constructed their study to investigate gender differences, and nine studies (Category D) reported gender differences despite not being a central focus of their methodology. A majority of the papers in these two categories

suggested that women both reported more distress and used more services than men, echoing findings of sex differences in the general caregiving literature.

The articles in these two Categories mirrored approaches adopted by the general caregiving literature in the use of a sex difference paradigm to compare groups of men with groups of women (e.g. Zarit, Todd & Zarit, 1986). For example, men have been described as using instrumental or problem-focused coping, in contrast to women who use emotion-focused or avoidant coping (DeVries, Hamilton, Lovett & Gallagher-Thompson, 1997; Garity, 1997; Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000; Lutzky & Knight, 1994).

Most of these studies used standardised questionnaires to assess burden, depressive symptomatology and coping. Some of the findings were difficult to compare because of the differing use of terminology and the ways in which these phenomena were assessed and operationalised. This has been recognised as a problem with coping research in general (Kneebone & Martin, 2003; Matson, 1994), and consequently, some findings appeared contradictory. Adler, Wilx & Gunzelmann (1996) described husband caregivers as experiencing more worry, in contrast to wives experiencing more stress. However, Sparks, Farran & Donner (1998) indicated that wives reported worrying more than husband and daughter caregivers. Ashley & Kleinpeter (2002) reported that wives sought more social support than husbands, but that they also used more avoidance strategies. Borden and Berlin (1990) found that women reported higher levels of distress, but that their gender was not a correlate of coping strategies. Parks & Pilisuk (1991) described women as having a more affective response to caregiver burden than men, and were more likely to use fantasy as a coping style. Lutzky & Knight (1994) described women as being socialised to use coping skills which were less effective for alleviating distress, thus suggesting an explanation of why women report more distress than men.

One study attempted to differentiate gender from other variables as a possible covariate of, or mediating factor for, coping strategies. Rose, Strauss and Neundorfer

(1997) found that caregivers reporting high levels of distress were more likely to use the emotion-focused coping strategy of wishfulness, in contrast to caregivers reporting low levels of distress using acceptance and instrumental coping (problem-focused coping). Interestingly, although there were gender differences in the levels of self-reported distress and the use of specific coping strategies, Rose and colleagues found that the relationship between coping strategies and distress held regardless of the gender of the caregiver. A similar finding was reported in Borden and Berlin (1990) who found that even though women reported higher levels of distress than men, gender was not a correlate of their coping strategies. Rose et al. (1997) suggested that it is possible that distress is a function of coping strategy rather than gender: that men who cope in the same way that women tend to, end up distressed like most women caregivers.

Interestingly, some of the researchers in this Category remarked on the limitations of adopting a sex difference paradigm, and recognised that there may be a gender bias operating in self-report methods of data collection (Hooker, et al., 2000; Lutzky & Knight, 1994). More recently, reviewers of the general caregiver literature have strongly suggested that gender needs to be investigated in more detail to determine how it moderates caregivers' responses to burden (Vitaliano, Scanlan, & Zhang, 2003). Several articles mentioned significant within-group variations for men and women but were unable to analyse this further due to the restriction of categorising participants solely by their biological sex. Although, criticisms of sex difference research have been appreciated within the health behaviour field for some time (Addis & Mahalik, 2003; Mechanic, 1978), it appears that these have yet to be generally incorporated into dementia caregiver research.

1.3.2 Studies reporting no gender differences (Category E, Table 1)

There were four studies reporting no gender differences. This low number was unsurprising given a general publication bias against reporting non-significant results (Sterling, Rosenbaum, & Weinkam, 1995). One article reported on an educational

programme designed to develop caregivers' competency and found no relationship between gender and the coping ability of spouse caregivers (Chiverton & Caine, 1989). Another article (McConaghy & Caltabiano, 2005) reported no differences between male and female carers on measures of burden, depression, coping and life satisfaction. In this study, no discrimination was made between the relationship of the carer to the care-recipient so that husband and wife caregivers responses were not analysed separately from other types of caregiver relationship. Saad et al., (1995) surveyed the coping strategies of the carers of 109 dementia patients using Pearlin et al.'s (1990) measure of dementia caregiver coping. They found that active problem-solving coping strategies seem to be of more benefit to carers. However, none of the coping strategies described were used significantly more by one gender than the other.

The final article in this Category presents an interesting interpretation of the absence of gender differences in coping with caregiver stress. Pot, Deeg and van Dyck (2000) tested the hypothesis that the personal, psychological, sociological and health resources of informal caregivers may exaggerate or attenuate caregiving stress. This was based on a common assumption made of caregivers: that their personal circumstances may help or hinder their roles in caregiving. Their study surveyed 166 caregivers of people with dementia and measured coping strategies (problem-focused, emotion-focused), neuroticism, physical functioning, received emotional and instrumental support. They concluded that no matter how they arranged the data in their multivariate analysis, either with the group of caregivers as a whole, or as a series of comparison sub-groups (e.g. spouses vs. non-spouses, men vs. women), no resource acted as a moderator for caregiver stress. They concluded that caregiving stress is more strongly related to the perception of the pressure experienced in caregiving rather than the resources available to the caregiver.

1.3.3 Studies focusing exclusively on men (Category F, Table 1)

Nine research articles were identified focusing exclusively on male carers of people

with dementia. It was anticipated that this category of articles would provide some useful insight into men caregivers' coping given the limitations of sex difference research outlined above. The studies, sample, research methodology and major findings within the context of coping are summarised in Table 2 below.

With the exception of the research carried out by Kramer, all of the papers used a semi-structured interview methodology with small groups of men caregivers. These papers appealed to a common, descriptive use of the term coping rather than applying coping theory. In contrast, Kramer (1997) considered how men appraised the caregiving situation in terms of strain and gain.

Kramer's (1997) research comprised a cross-sectional, multivariate analysis of several standardised measures to investigate the predictors of positive appraisals of caregiving. She found that 'husbands who appraised the highest levels of gain were those who were less educated more satisfied with their social participation, in better health, and who reported greater use of problem-focused coping' (Kramer, 1997: p. 246). The regression analysis also suggested that, for men carers, predictors of gain were independent from predictors of strain.

It was noticeable that each of the articles in this Category were cross-sectional in design and thus limited in their predictive value. Although determining cause and effect was unlikely to have been the aim of the qualitative studies, longitudinal methodologies are needed to assess the effectiveness and relevance of the suggestions made in these articles. Kramer (2000) has since followed up the cohort from her 1997 study, although she did not re-assess coping. She focused on the differences between men caregivers who continued to look after their wives at home and those who had placed their wives in residential care. Those husbands who continued to care for their wives at home experienced increased difficulties with their wives, whilst their resources for dealing with the stressors had

Table 2: Articles reporting research and interventions focused on men caregivers of dementia addressing coping in respect of caregiver problems.

Study	Sample	Research Methodology	Major Findings in the context of coping
Cahill (2000)	N = 26 husband caregivers. Age range: 55 – 87 years.	Cross-sectional. Semi-structured interview designed to collect quantitative data about the care receiver (health status, cognitive impairment and physical dependence) and qualitative data about the caregiver (reasons for caregiving, care tasks done, time spent caring, formal and informal support received and satisfaction with role).	No model of coping used, a little discussion of coping in dementia caregiving research. Occasional description of men's coping in some situations: care roles modelled on work roles; some men view domestic tasks as new and learning opportunities; some men consider incontinence as routine aspect of care, pragmatic, instrumental approach to problems; satisfaction with care role that continues the validity of the marriage;
Davies, Priddy & Tinklenberg (1986)	N = 6 and 5. Age range: 63 – 83 years.	Descriptive report on support groups for male caregivers of Alzheimer patients. Describes development of pilot programme and suggestions for recruitment and format of group. Use of case illustrations to describe coping styles 'familiar to men'. No formal evaluation described.	No model of coping used. Description of coping styles through case illustrations. Men did not want to develop problem solving coping, but were interested in sharing personal experiences. Description of variation of male caregivers: the new caregiver; the younger caregiver; and the depressed caregiver. Discussion of issues raised in the groups: Need for validation, need for information, social network issues, concern with physical care.
Harris (1993)	N = 15 male caregivers	Cross-sectional. In depth interviews of male caregivers from diverse backgrounds, using a general interview schedule, covering the following areas: commitment, patient's impairment and duration, caregiver history, direct care performed, new roles learned, stresses/burden, coping strategies, motivation, interpersonal relationships, satisfactions, social support, services used, barriers to service, service suggestions, retirement decisions, and losses.	No model of coping used, no discussion of coping literature, or interpretation of analysis. Interviews analysed into common themes and generated a typology of male caregivers. Men described as using following coping strategies: control, a problem solving approach, respite care, a structured regime, and time for themselves outside the home. Some very short descriptions of situations where these are used, but this is for illustrative and descriptive purposes.
Harris (1995)	N = 15 husband caregivers. Age range: 68 – 88 years.	Cross-sectional. General interview schedule used with topics covering: commitment, level of care-receiver's impairment and duration of illness, caregiver history, direct care performed, new roles learned, stresses/burdens, coping strategies, motivation, interpersonal relationships, social support, services used, barriers to service, service suggestions, retirement decisions, and losses.	No model of coping used. No discussion of the coping literature. Summarises a typology of men caregivers through four case studies: the worker, the labour of love, sense of duty, and at the crossroads. Coping strategies can be inferred from case studies: treating caring as 'work' and acquiring new skills, use of planning, caring as devotion not duty, using respite care, caring as a duty, using other family members to support caring, setting a routine, and sharing frustrations.

Study	Sample	Research Methodology	Major Findings in the context of coping
Harris (1998)	N = 30 son caregivers.	Cross-sectional. Qualitative analysis of semi-structured interviews. Four main topics in the interview schedule: history, effect of, role as caregiver; stress/burdens and coping strategies; role of self within, and impact of dementia on, interpersonal and family relationships; and meaning and motivation of the caregiver role.	No model of coping used. No description of which strategies used for which problems or when. Coping strategies used by sons interpreted by researcher. N = 19 used problem solving approach; n = 11 used immersing self in work; n = 10 used confiding with wife, n = 10 sought solace and support in their religious convictions.
Kramer (1997)	N = 74 husband caregivers.	Cross-sectional. Multivariate analysis (multiple regression) of structured interview consisting of 14 self-rated measures of: demographics, stressors/care receiver characteristics, health, satisfaction with social participation, coping, strain (caregiver burden), gain (caregiving satisfaction).	Coping assessed in the context of appraisals of 'strain' and 'gain'; to see whether these appraisals are a function of stressors, personal demographics and the husband's resources. Stressors strongest predictor of strain, Gain not related to stressors, thus equally likely from variety of caregiving situations. Association between lower education and gain. Suggested that problem solving coping is related to gain, emotion focused coping related to strain. Social support is strongest predictor of strain and gain.
McFarland & Sanders (1999)	N = not reported, male relative caregivers.	Cross-sectional. Focus groups designed to inform development of support services for men caregivers. Qualitative analysis/interpretation of group discussions.	No model of coping used. Personal reflections on how men coped reported, but rarely in the context of specific problems. Many men indicated that using services was an admittance of failure of their caregiving. Men preferred mixed support groups to help discuss emotional impact and learn coping styles from women. However, all male psycho-education groups desirable. Men reported education/information helped feeling in control.
Russell (2001)	N = 14 husband caregivers. Age range: 68 – 90 years.	Cross-sectional. In depth, open ended interviews using an interview schedule. Questions aimed to elicit: perceptions of caregiving roles, commitment and responsibility; levels of difficulty, satisfaction and gratification; and coping skills.	No model of coping used, no discussion of coping in discussion. Interviews analysed inductively into three themes: feelings of isolation and invisibility of care work; a style of caregiving that jointly utilises management and nurturing; and feelings of commitment, responsibility and devotion. Some implicit descriptions of coping responses to frustration: "staying focused", "trying to keep all this in perspective". Men describe the importance of: using respite care; continuing with interests and activities outside of the home and the caregiving situation; coping with wife's 'confused' perception of the world by 'understanding their reality'; and the "One day at a time" approach to caregiving.

Study	Sample	Research Methodology	Major Findings in the context of coping
Siriopoulos, Brown & Wright (1999)	N = 8 husband caregivers	Cross-sectional. Phenomenological analysis of semi-structured interviews (not described), with contributions from researcher's field notes and reflective journal.	No model of coping used. The five 'themes' considered meaningful by the researcher were: quality of previous relationship, loss, caregiving burden, coping and support methods, and effects of AD. Coping described as using assistance, establishing a routine, maintaining normal function, holding on and letting go of memories, and humour. Some description of which coping strategies used most in particular situations.

remained stable. However, this group of husbands appraised the functional limitations of their wives as less stressful and reported lower levels of depression. Kramer's results were consistent with previous research showing husbands tolerating stress better over time (Zarit et al. 1986) and depression levels remaining lower over a two year period than wife caregivers (Zarit & Whitlach, 1992). In contrast, those husbands whose wives entered residential care saw their resources improve and appraisals of stress decrease, but saw no change in their psychological well being. Kramer (2000) suggested that this indicates the beginning of a bereavement process for this group of husbands.

The other eight papers in Category F used interviews to explore their participants' experiences of dementia caregiving. In her three studies, Harris (1993; 1995; 1998) categorised her participants into typologies such as 'the worker', 'the labour of love', 'sense of duty', 'at the crossroads'. These typologies described the variation of experience with which many male caregivers may identify, but no link was made with any psychological model of coping. Harris (1995) suggested specific interventions tailored to the coping categories she was identified, but these remain hypothetical and unsupported by either empirical or theoretical evidence.

Davies, Priddy, and Tinkelberg (1986) described the development of a support group for men, but they did not describe any assessment of the participants nor did they evaluate the efficacy of the group being reported. Davies et al.'s paper was essentially atheoretical of a model of stress or coping, and inferred coping styles through case illustrations of the male carers presented in the study. Similarly, McFarland and Sanders (1999) described focus groups designed to inform the development of support services for male caregivers. Although coping was alluded to, it was incidental to the concerns of their article, with their focus being the improvement of low take-up of services by male caregivers. Their study reported the ambivalence men may experience in response to caregiving. Some men suggested a preference for a mixed support group in which women caregivers could assist "them in facing the emotional effects of Alzheimer's Disease and [teach] them beneficial

coping techniques” (p.281). Yet they also intimated that an all-male context would be preferred to learn ‘techniques’ for caregiving.

The McFarland and Sanders (1999) study also suggested a relationship between education and caregiver’s appraisals about caregiving. Specifically, that the more educated male caregivers were about caregiving, the more control they believed they would have over the disease. The broader caregiving literature has suggested that appraisals of control of the caregiving situation are related to caregivers’ beliefs about caregiving (Szabo & Strang, 1999). However, Kramer’s (1997) finding that higher education is associated with lower gain appraisals in male caregivers, indicated that the relationship between beliefs and appraisals is more sophisticated than McFarland and Sanders (1999) suggested. Interestingly, Kramer (1993) also showed that this relationship between higher education and lower appraisals of gain was not found in Caucasian women caregivers. This suggests that research would benefit from considering how gender, education, and caregiver strain and gain interact.

Cahill’s (2000) study used male caregivers’ own descriptions and personal interpretations of their role to supplement quantitative measures about the care-receiver. The greater detail of intimate care offered by male carers described in this study contradicts the widely held view that men cannot act competently in this domain, and also showed that they receive some satisfaction from the caregiving role. Cahill argued that for the majority of men she interviewed, their ‘motivation to care and their involvement in the role was similar to that demonstrated by women’ (p. 66). Similar to the articles by Davies et al. (1986) and McFarland & Sanders (1999), Cahill did not refer to any coping theory or model. In all three articles, suggestions for service delivery and the group interventions were made, but it was difficult to quantify the usefulness of these suggestions given that no evaluation was described.

Russell’s (2001) study used in-depth, open-ended interviews to explore several questions about men caregivers of wives with dementia. One question focused on the

coping strategies used by elderly men to deal with the ongoing challenges and demands of caregiving. Russell identified three themes to answer this, but did not address the question about coping in a systematic way, and only made one explicit reference to coping in the results and discussion sections of the paper. He referred to the emotion-focused strategies of 'staying focused' and 'trying to keep all this in perspective' that some of his participants used in coping with their frustrations. There are some other descriptions of men using coping strategies in the rest of the results section, but as with the other papers in this Category of the literature review, they remained descriptive and did not make use of any coping theory or model.

Of the qualitative studies in this Category, Siriopoulos, Brown and Wright (1999) uniquely specified their thematic examination of interview data by using Giorgi's phenomenological approach to discourse analysis. By using such a method, the authors intended to describe the experiences and needs of caregiving from the husbands' point of view. Their conclusions are similar in character to the majority of the studies in this Category in describing the variation of men's caregiving experiences, but again no reference was made to any model or theory of coping.

1.4 Discussion

The current literature review sought to interrogate the body of research into how men cope with the burdens of caring for a relative with dementia. The broader body of research indicates that men experience caregiving differently from women, and it was therefore anticipated that there would be an awareness that investigating gender within the caring context would be a valid enterprise. However, despite suggestions that gender may be an important factor, the majority of published research has not considered investigating gender in any depth. For the few studies that have considered gender, their focus has been on sex differences rather than considering gender as a mediating variable between coping and burden.

The bulk of the caregiver-coping research reviewed used multivariate analyses of questionnaire surveys to explore the links between stress/strain/burden, coping, and distress/depression/health. Only one study exclusively investigated men using this methodology (Kramer, 1997). The majority of articles that focused exclusively on men used interview-based methodologies and qualitative-oriented analyses.

The current literature search offered three critical observations on the articles reviewed: addressing individual differences; operationalising coping; and self-report bias. These criticisms apply both to the questionnaire studies of groups, and those using individualised in-depth interviews.

1.4.1 Addressing individual differences

Only two of the studies using a multivariate design and analysis attempted to explain the mediating factors between strain/burden and coping without the limitations of a categorical independent variable of sex (Kramer, 1997; Rose, Srauss & Neundorfer, 1997). Comparing the characteristics of men with women caregivers, without considering the variation of those characteristics within each gender, limits the application of results and does not provide any detail about the processes that might mediate burden and coping

strategies. Interview-based research claimed to describe individual experiences of men coping with dementia caregiving, but these concluded with generalised typologies (e.g. Harris, 1995; Siriopoulos, Brown & Wright, 1999). No study attempted to relate individual coping to any detailed cognitive process. Kramer's (1997) work stands alone in employing multivariate regression analysis to explore the variations in men's appraisals of strain and gain.

Further sophistication is required to understand how coping can account for individual differences within the genders. DeVries et al. (1997) examined individual differences in the cognitive and behavioural coping skills of men and women caregivers of cognitively and physically impaired older adults. Although women caregivers used more diverse coping strategies than men, there were no significant differences in the reported utility of the coping strategies. Indeed, both men and women agreed on the strategies they found the most useful.

It is plausible that men and women use the same coping strategies, as some studies in the current review suggest (Pot et al., 2000; Saad et al., 1995). However, the varying appraisals and explanations for the functions of coping that are often reported in research, may be mediated by the caregiver's sense of their gender identity or role. None of the research reviewed here assessed gender identity or role. Clarifying how people articulate and explain their coping intentions, and whether this is related to appraisals mediated by gender socialisation, would help inform the development of interventions for carers.

1.4.2 Operationalising coping

Those studies using questionnaires to operationalise the assessment of coping suffer many of the same problems present in the general caregiving and coping literature (Carradice, Beail, & Shankland, 2003; Ferguson & Cox, 1997; Kneebone & Martin, 2003; Matson, 1994): various measures of coping are used, and different models of coping are explicated, compromising the comparison of findings across studies. These problems are

magnified when studies suggest contradictory patterns of coping strategies.

None of the interview-based studies used an explicit psychological model of coping to explain the men's responses to caregiver stress but limited themselves to surface level description. Exploring coping as a psychological construct may not have been a primary focus for these studies, but the absence of an explanatory framework suggests that this body of research has the potential for increased sophistication and its relevance to the development of interventions. In Lazarus' (1999) view, any analysis of adaptation or maladaptation should involve an appreciation of the conceptual foundations of coping theory. For male caregivers, incorporating an understanding of how gender-related variables, such as men's gender identity and gender role, may mediate cognitions, motivations, emotions and actions is one way in which this can be done.

1.4.3 Self-report bias

Self-report bias, where participants may give answers to questions that are either too heavily reliant on memory and/or censor them via social desirability, is evident in all the studies in this review. This is acknowledged by some of the authors as problematic, but not in much detail.

Gender differences exist in the self-report of health problems (Addis & Mahalik, 2003; Bosworth et al., 1999; Courtenay, 2000; Hooker & Siegler, 1993), and of distress and burden in general (Lutzky & Knight, 1994). Vitaliano et al. (2003) suggested that selection bias in face-to-face self-report research may operate differentially with men and women, and this is supported by Stroebe and Stroebe's (1989) research on widows. Stroebe and Stroebe (1989) discovered minimal differences in self reports of depression between widows and widowers through interview, but significantly higher levels of self-reported depression in widowers than widows in postal questionnaires. Similar method-related gender differences have been elicited when investigating the emotional experiences of men and women. Respondents tend to report gender-stereotyped emotions in interviews and

questionnaires (for example, men disclosing pride, women reporting affection: Brebner, 2003), but these gender differences are not evident using diary and observation methods (Timmers, Fischer & Manstead, 2003).

1.5 Conclusions and Implications for further research

A minority of papers on caregiving in dementia focus exclusively on men and highlight the need for better conceptualised and designed research to understand men's coping with dementia caregiving. Greater specification of coping functions and behaviours, and how these change over time, will help to inform more efficacious interventions. Despite the use of quite diverse methodologies, Harris (1995) concluded similarly to Kramer (1997) that husbands are poorly understood in comparison with wives because they 'adapt to the caregiving role differently, experience social isolation differently, fare differently emotionally in their caregiving experiences, and thus may respond differently to various services and counselling approaches' (Harris, 1995; p105).

Several conclusions arise from the current literature review. Some derive from criticisms of the studies above and others from the general literature on coping, men caregivers and caregiving. Many articles reported that recruiting men was difficult and may have to be tackled with more creative designs and recruitment procedures. This could be done by engaging men through an awareness of how masculinity operates to influence their thoughts and behaviours (Addis & Mahalik, 2003). In caregiver interventions this could be done by describing support groups in terms of a caring skills course, or asking experienced male caregivers to explain how new caregivers could tackle the difficulties of dementia caregiving. A further observation made in relation to the problem of recruitment, is that none of the studies reviewed above have reported in detail on men who do not appear to cope well with dementia caregiving. These men may not use services, and perhaps are unlikely to participate in research, yet their experiences would be invaluable in determining what support or intervention would be beneficial.

Acknowledging individual differences between men and their relationship with the care-receiver should also be an important aspect of research design. It is often acknowledged that personal history and beliefs will affect appraisals of caregiving situations and hence coping functions and behaviours, but these are rarely operationalised in research designs. Differentiating between son and husband caregivers is an obvious facet of individual differences, but differences also exist within these groups. If men are to be compared to women, or other caregiver groups, then treating gender as a source of individual difference is preferable to confusing it with the biological category of sex.

The means by which men cope with dementia caregiving has been limited in two main areas: understanding the individual differences between men, and applying a psychological model of coping. For research to be useful in the development of interventions, such limitations must be addressed. An intervention's efficacy is determined by its ability to address the varied problems of individuals. Accounting for the different experiences caregivers bring to their role within a psychological model of stress, appraisal and coping, can contribute to the effectiveness of an intervention.

Although the specific issues facing men carers are important ones, they are relatively neglected in the literature and to date poorly examined. It is clear that some men find it difficult to adjust to a caring role (Archer & MacLean, 1993; Barusch & Spaid, 1989) and do not access health care services and interventions optimally (Addis & Mahalik, 2003; Toseland & Rossiter, 1989). Deepening the sophistication of our knowledge of how different men cope with the challenges of dementia caregiving should not only enrich our understanding of the caring role and inherent challenges, but also improve the development of appropriate interventions.

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2.0 Research Report: Men caring for wives or partners with dementia: Masculinity, strain and gain.

Men caring for wives or partners with dementia: Masculinity, strain and gain.

Kevin L. Baker

Abstract

Men are increasingly involved in caring for their wives and partners with dementia. There are known differences in the ways that men and women report burden, cope with the demands of caregiving and use services, but relatively little research has described the variation of responses that men make to the carer role. Some research with husband carers has shown that strain and gain are differentially predicted from variables associated with the characteristics of the carer and the care-receiver, as well as background and context variables. An appreciation of the role gender plays in these appraisals is notably absent from the literature.

This cross-sectional study reports on a multivariate analysis of caregiver appraisal of strain and gain that includes measures of gender identity and gender role conflict. Results indicated that traditional beliefs about masculinity are important predictors of strain, but are secondary to the nature of the memory and behavioural problems of the care-receiver. For appraisals of gain, traditional beliefs about masculinity are the most important predictors out of those assessed in this study.

The findings have implications about the importance of incorporating an understanding of masculinity and gender in clinical work and research with men caring for wives or partners with dementia.

Key words: dementia care, gender, masculinity, male caregiver, burden, coping.

Target Journal: Aging and Mental Health.

2.1 Introduction

Since the mid-1980's the high level of involvement of older men in caring for their wives has continued to surprise researchers (Green, 1988; Rowlands, 1998). Changing demographics mean that more men are involved in informal care. In the UK, over the age of 65, men are in fact more likely than women to be caring for someone in their own home (Office of National Statistics, 2004). Husband carers are on average the oldest of the subgroup of carers and report spending more hours providing care than other caregiver groups such as wives, daughters, daughters-in-law and sons (Stone Cafferata, & Sangl, 1987; Chang & White-Means, 1991). It is also apparent that as these men age, the more hours of care they provide (Office of National Statistics, 2005), and over half report receiving no help from others (Stone et al., 1987).

Compared to caregiving in general, dementia care has been shown to involve more problems and difficulties (Baumgarten et al. 1992; Ory et al., 1999). As dementia progresses, the carer is faced with changes in their spouse's character and behaviour to which they need to adapt (Zarit & Edwards, 1999). Husbands, in particular, may find themselves actively engaged in household tasks for the first time, such as preparing meals, administering medications, feeding, turning and bathing their wives/partners (Barusch & Spaid, 1989; Chang & White-Means, 1991; Miller & Cafasso, 1992).

The majority of research into the consequences of dementia caregiving has focused on negative affective outcomes such as burden. Burden has most frequently been operationalised using the Zarit Burden Interview (ZBI: Zarit, Reever, & Bach-Peterson, 1980), and generally assessed with a single summary score. The theoretical research on caregiver burden has preferred to use other instruments designed to tap multidimensional constructs (Vitaliano, Young & Russo, 1991), but these are rarely used in intervention studies (Knight, Fox & Chou, 2000). O'Rourke and Tuokko (2003) have suggested that the ZBI can be confidently used to assess Role Strain and Personal Strain as distinct factors, where Role Strain refers to the burden perceived as a direct consequence of the role, and

Personal Strain refers to feelings of inadequacy and uncertainty. The use of multi-factorial structures to explain burden should offer more detail that can be applied in interventions, and can be placed within general models of stress and coping (Lazarus, 1999; Lazarus & Folkman, 1984). For example, beliefs that one's current and future resources are insufficient to meet demands can lead to secondary appraisals of burden that precede negative physical and psychological health outcomes (Lazarus, 1999).

Despite the majority of the literature focusing on the negative outcomes of dementia caregiving, there are individual differences in responses to the caregiving situation. Some carers report that they cope quite well (Haley, Levine, Brown, Berry & Hughes, 1987), and over half of carers report that they can identify some satisfying aspects to their role (Nolan, et al., 1996). Many caregivers report that they feel an increased sense of self-worth, competency, and an enhanced sense of meaning and closeness to the person they are caring for (Archbold, 1983; Kramer 1997a; Motenko, 1988; Reese, Waltz & Hageboek, 1983).

More recently, research has shown that the predictors of positive outcomes are distinct from those predicting negative ones (Gold et al, 1995; Kramer, 1993, 1997a, 1997b; Rapp & Chao 2000). Strain is associated with the number of memory and behaviour problems, duration of caregiving, and emotion-focused coping, while Gain is associated with problem-focused coping and educational background (Biegel et al., 1991; Miller, 1989; Kramer, 1997b; Lawton et al., 1991). Assessing both positive and negative outcomes is likely to enhance understanding of the variability of responses to caregiving, and provide a basis for more sophisticated and effective interventions (Lazarus, 1999).

2.1.2 Gender differences

The vast majority of research that has included gender as an independent variable has used a sex difference paradigm. These studies have compared men and women across various measures relevant to dementia caregiving. In comparison to men, women caregivers have repeatedly been shown to report higher levels of burden, depressive

symptoms and impaired health (Barusch & Spaid, 1989; Vitalliano, Scanlan, & Zhang, 2003). Sex differences have also been reported in coping, with women typically described as using emotion-focused coping and men problem-focused coping (Ashley, & Kleinpeter, 2002; Lutzky & Knight, 1994). Women are also described as using a more limited range of coping strategies than men (Pearlin & Schooler, 1978).

However, these findings must be read with caution as some studies have reported finding no gender differences on measures of coping and burden (Chiverton & Caine, 1989; McConaghy & Caltbiano, 2005; Pot, Deeg and van Dyck, 2000; Saad et al., 1995), and some report husbands experiencing significantly more burden and distress than other carer groups (Samuelsson, Annerstedt, Elmst, Samuelsson, & Grafström, 2001). Such conflicting findings could be explained through variation and error in the methodology and measures used, but some reviewers have suggested that a deeper understanding of caregivers' responses to burden is required. In their meta-analysis of gender differences in caregiver outcomes, Miller and Caffasso (1992) suggested that the psychological processes relevant to caregiving may be different for men and women.

The observation that groups of men and women differ on a set of characteristics reveals little about the processes responsible for those differences (Addis & Mahalik, 2002; Mechanic, 1978). These processes may be biological, psychological or cultural, but if this is not addressed within the research design, the interpretation of sex differences remains speculative at best. Research using a sex-difference paradigm can rarely account for within-group or within-person variation. Not all men are the same, nor will all men behave in a similar manner given similar circumstances. Consequently, it is extremely difficult to apply sex difference research findings clinically and develop interventions where individual variation needs to be accounted for.

Deepening our understanding about research on sex differences can be facilitated by examining the literature on gendered response bias. Gendered response bias is known to operate when asking men and women about negative and positive affect: men are more

reluctant to report depressive symptoms (Brody & Hall, 2000; Conway, 2000) and women are more likely to report sadness, and place more importance on attending to lowered affect (Salokangas, Vaahtera, Pacriev, Sohlman & Lehtinen, 2002; Sigmon et al., 2005).

Although men and women may experience stress and distress similarly, men tend to talk more freely about the physical aspects of their distress than their emotions, and women more readily talk emotionally about their response to stressful situations (such as shame and guilt) (Danielsson & Johansson, 2005). The implication of this gendered response bias is that comparing depressive symptomatology between women and men becomes a complex enterprise. Consequently it strengthens the argument to investigate variation within the genders rather than comparatively.

2.1.3 Research on husband caregivers

Very few researchers have focused exclusively on male caregivers in an attempt to understand more about how this group responds to the demands of caring. Kramer's (1997b) research is one of the few studies to use a quantitative methodology to explore the differential predictors of strain and Gain in husbands caring for wives with dementia. Her study used a regression analysis on a selection of independent variables selected as representative of background and contextual variables and resources, to explain the variation found in husbands' appraisals of strain and Gain. She found that stressors (for example the memory and behaviour problems of the care-receiver) were one of the strongest predictors of strain but displayed no relationship with Gain. This means that appraisals of Gain are equally likely to vary across husbands regardless of the stressors of their caring situation. Kramer also described a surprising negative association between education and appraisal of Gain, such that more highly educated husbands appraise reduced Gain in comparison to husbands of lower educational attainment. She explained her findings by drawing on Thoits' (1986) idea that employment and educational role identities may influence one's perception of social status and sense of purpose and

meaning. She argued that these would act differentially on men's and women's life experiences, and so may be adaptive to caregiving (for women) or maladaptive (for men). Kramer offers several possible explanations drawing on this thesis: that more educated husbands may perceive a lower status in caring; that they don't see the daily tasks of caring as rewarding as intellectual activity; and that the financial burdens of dementia care may be perceived in higher terms of relative loss.

Kramer (1997b) also reported that coping acted differentially on husbands' appraisals of strain and Gain. This reflects findings from the general caregiving research where instrumental problem-focused coping is associated with positive affect and appraisals of Gain, and emotion-focused coping is associated with negative mental health outcomes and strain (Lutzky & Knight, 1994; Rose, Strauss & Neundorfer, 1997). A problem-focused approach to coping is often an attempt by a person to take control of the stressful situation in a proactive, instrumental way. If successful this can help the caregiver achieve a sense of mastery over the situation and defend from feelings of helplessness. Miller (1987) described that both husband and wife caregivers make attempts to take control, but in contrast to husbands, wives find it more difficult to assume authority over their spouses as it runs counter to their experience of their roles.

Kramer (1997b) found that emotion-focused coping was the strongest predictor of strain in husband caregivers. Types of strategies that husbands may use in this style of coping are suppression of feelings, denial, self-blame, wishful thinking and avoidance. These may offer temporary relief from the stresses of caregiving but do little to effect control of a situation. For some men, suppressing feelings is a fundamental aspect of their sense of masculinity (Adams, 1994), and can lead to using alcohol and drugs as a way of coping (Carver, Scheier, & Weintraub, 1989). Understanding the contexts in which men suppress their feelings would seem to be important in helping men caregivers increase the effectiveness of their coping.

Kramer's research (1997b, 2000) on husband caregivers is clearly important as it is a

paradigm shift in investigating variation in husbands' responses to dementia caregiving. In the absence of such research, an over-reliance on simplistic gender comparisons would limit evidence on which to base interventions for male caregivers, and consequently restrict the support available to the variety of caregiver needs. However, it remains to be seen whether constructs about men's coping with distress from other fields of research can contribute to furthering our understanding of husband caregivers.

2.1.4 Gender identity and gender role conflict.

Research in health, health behaviours, and help-seeking has often applied concepts from the literature on gender to understand how men and women differentially respond to illness (Addis & Mahalik, 2003; Berger, Levant, McMillian, Kelleher, & Sellers, 2005; Courtenay, 2000). Two concepts from these areas that have been widely applied to psychological research with men are gender identity and gender role conflict.

2.1.4.1 Gender Identity. Gender identity, or sex role orientation, refers to how a person identifies themselves as masculine or feminine. Research in this area was initiated by Bem and later by Spence and colleagues with their self-report measures of the Bem Sex Role Inventory (BSRI; Bem, 1974) and the Personality Attributes Questionnaire (PAQ; Spence & Helmreich, 1978). Both of these scales require participants to select adjectives which they think best describe them. These adjectives had been previously rated as those most desirable in men, the 'masculinity' scale, and in women, the 'femininity' scale. The titles of the scales were later felt to be problematic and restrictive, and were renamed 'instrumental' and 'expressive' (Smiler, 2004; Spence, 1991; Spence & Helmreich, 1980).

Both of the masculine/instrumental and feminine/expressive traits are viewed as socially desirable attributes for both genders rather than mutually exclusive categories. The measures offer a way of assessing variations within the genders about how individuals view themselves (Spence & Buckner, 2000). In general, women tend to report more

expressive traits and men more instrumental traits, although recent reviews describe women's levels of self-reported instrumentality are increasing (Spence & Buckner, 2000).

The measures of instrumentality and expressiveness can be understood as an expectation about a socially desirable response, with the expectation that men tend to think of themselves as more instrumental, and women as more expressive. Consequently, men who think of themselves as traditionally masculine will respond with higher instrumental scores than men who think of themselves as less traditionally masculine.

Superficially, the BSRI and PAQ measures of instrumental and expressive identity are similar to the concept of problem-focused and emotion-focused coping, but there are important differences. Rather than asking how an individual would act in a given situation, the PAQ presents a selection of socially desirable choices favoured by an individual in thinking about their identity. It is unclear how these may relate to appraisals of coping in stressful situations. Whitley (1983) reported that people rating themselves highly on masculine identity presented with low levels of self-esteem and more depression and anxiety. Heppner, Walther and Good (1995) concluded that the interpersonal qualities evident in the feminine/expressive identity are associated with a problem-solving approach to strain in both sexes. Although, there is support for a differential relationship between coping and positive and negative appraisals in caregiving (Borden & Berlin, 1990; Kramer, 1997b; Rose, Strauss & Neundorfer, 1997), it is unknown whether instrumental and expressive identity is involved in this relationship.

2.1.4.2 Gender Role Conflict. Gender Role Conflict is a more recent approach to investigating masculinity that has focused on the negative consequences of living traditional masculine roles. O'Neil and colleagues developed the Gender Role Conflict Scale (GRCS; O'Neil, et al., 1986), based on observations that for some men, their adherence to a traditional form of masculinity leads to negative consequences for themselves and others. The conflict resulting from the socialised gender role is described

as operating at different levels of experience (O'Neil, 1995), stemming from stereotyped beliefs, and experienced behaviourally and emotionally as conflict within the self and with others. In developing an assessment scale to measure Gender Role Conflict, O'Neil and colleagues have identified four Gender Role Conflict patterns: Success, Power and Competition (SPC); Restrictive Emotionality (REP); Restrictive Affectionate Behaviour Between Men (RABBM); and Conflicts Between Work and Family Relations (CBWFR). (Further explanation of these constructs is in Appendix 11). Correlations of the PAQ and GRCS indicate that there is little overlap between their factors and suggest that they are independent constructs (Sharpe & Heppner, 1991; Sharpe, Heppner & Dixon, 1995). The PAQ is often operationalised as a measure of personality traits differentially applicable to the sexes (Spence, Losoff & Robbins, 1991; Thompson & Pleck, 1995), sometimes referred to as 'gender orientation', but can be thought of as cognitive schema (Bem, 1981). Whereas, the GRCS was designed to reveal men's experience with gender as defined by beliefs about traditional masculinity (Thompson & Pleck, 1995).

There have been several studies investigating the links between Gender Role Conflict and a number of measures of psychological well-being. Gender Role Conflict has been implicated in low self-esteem and higher levels of depression (Cournoyer & Mahalik, 1995; Good & Mintz, 1990; Sharpe & Heppner, 1991), higher levels of psychological distress, (Liu, et al., 2005), higher levels of anxiety (Cournoyer & Mahalik, 1995; Sharpe & Heppner, 1991), a reluctance to seek help (Berger, et al., 2005; Good, Dell, & Mintz, 1989), and less capacity for intimacy (Cournoyer & Mahalik, 1995; Mahalik, Locke, Theodore, Cournoyer & Floyd, 2001). Hill and Donatelle (2005) concluded, from their study of men over the age of 40, that Gender Role Conflict in older men may limit their perception of the availability of social support and consequently their ability to appreciate the beneficial effects of supportive relationships. This conclusion is supported by findings that Gender Role Conflict is predictive of men's negative attitudes towards psychological help-seeking (Robertson & Fitzgerald, 1992; Wisch, Mahalik, Hayes, & Nutt, 1995).

To date no research has been carried out using the constructs of Gender Role Conflict or Gender Identity in a male caregiving population. Although from the research highlighted above, one may hypothesise that, due to possible associations with low self-esteem, high levels of anxiety, and a limited capacity to perceive and seek social support, high levels of Gender Role Conflict will be associated with higher levels of strain.

2.1.5 Research question and Hypotheses.

To summarise, much research has assumed and found sex differences in burden and coping in caregiving without addressing the role gender may play. It would therefore appear apposite to investigate the contribution gender variables relevant to the concept of masculinity may make to a model of caregivers' appraisals of strain and gain. Marecek (1978) described how a person's awareness of their culture's approval or disapproval of a coping behaviour may determine how successful he/she is at coping. It seems logical to assume, then, that gender identity and role may mediate coping appraisals and behaviours. For example, a man whose identity derives from ideas about traditional masculinity such as independence, restrictive emotional expression, and not showing weakness, may experience the demands of caregiving for a wife with dementia as more stressful than a man who is comfortable with being dependent on others and expressing their emotional responses to the difficulties experienced.

The current investigation tested three hypotheses to explore the general research question: Are masculine gender characteristics important factors involved in the appraisals of strain and Gain in husbands caregiving for wives or partners with dementia? This was investigated through the following Hypotheses:

H1: Gender Identity and Gender Role Conflict will contribute significantly to appraisals of Role Strain in comparison to known predictors, such as memory and behaviour problems and duration of caregiving.

H2: Gender Identity and Gender Role Conflict will contribute significantly to appraisals of Personal Strain in comparison to known predictors, such as memory and behaviour problems and duration of caregiving.

H3: Gender Identity and Gender Role Conflict will contribute significantly to appraisals of Gain in comparison to known predictors, such as length of education.

2.2 Method Section

2.2.1 Design

The current study used a survey approach via postal questionnaires to investigate whether measures of Gender Identity and Gender Role Conflict can contribute to the prediction of husband caregiver strain and Gain. Measures of Gender Identity and Gender Role Conflict were assessed along with measures previously known to predict variance in Strain and Gain using a multiple regression analysis.

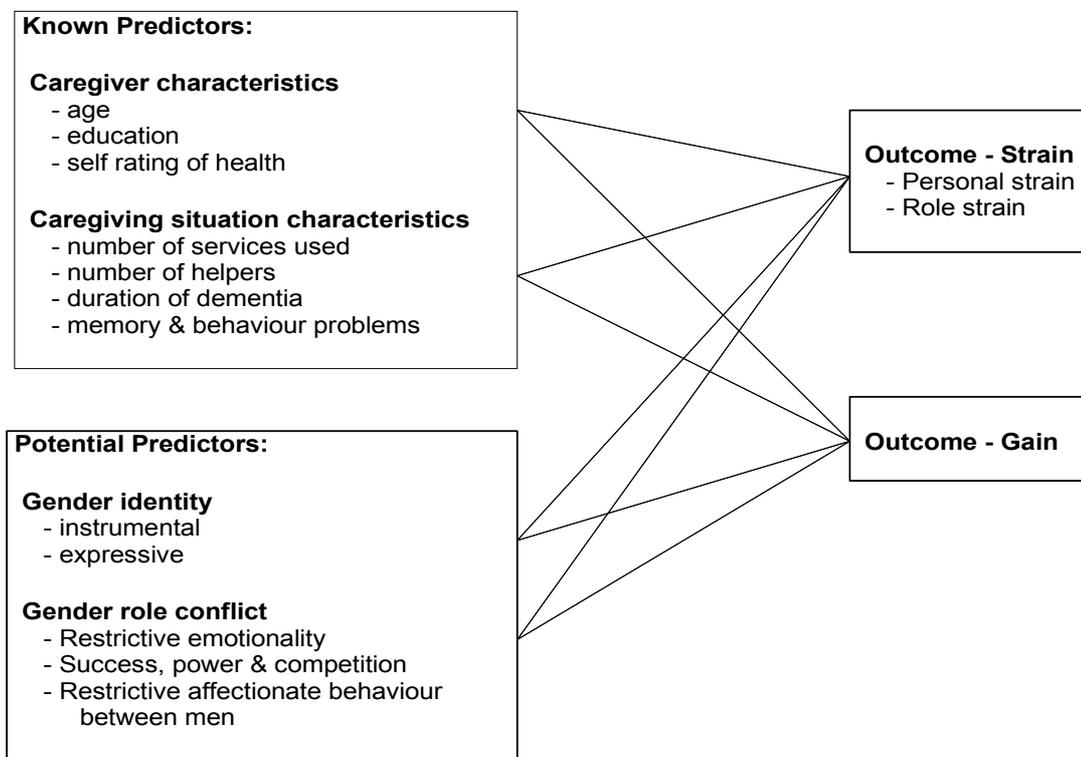


Figure 1: Schematic diagram of the research design showing the variables concerned.

2.2.2 Participants

The participants were men caring for their wives or partners who had a diagnosis of a dementia. They were recruited via two routes: locally through NHS day hospitals and community teams, as well as through the voluntary sector carers' groups; and distally through internet bulletin boards.

Thirty-three respondents completed the questionnaire through the internet. Locally, forty-seven participants were invited to participate in the research. Forty-two participants returned questionnaires, representing a response rate of 89%. Two participants did not return their consent forms, two participants did not complete large sections of the questionnaire, and one participant declined to continue with the study. In total, seventy participants' data was used in the analysis.

2.2.3 Measures

The questionnaire composed of seven sections labelled A to G. A copy of the full questionnaire can be found in Appendix 4.

Table 3: Description of the contents of the questionnaire.

Questions / Scales	Section in Questionnaire	Variable	Number of questions	Number of subscales
Age	A	IV	1	-
Years education	A	IV	1	-
Self rating of health	A	IV	1	-
Years married	B	IV	1	-
Duration of dementia/caring	B	IV	1	-
Number of helpers	B	IV	1	-
Number/Use of services	B	IV	1	-
Memory & Behaviour Problems (MBPC-R)	F	IV	24	2
Gender Identity (PAQ)	C	IV	16	2
Gender Role Conflict Scale (Adapted)	E	IV	15	3
Burden/Strain (B-ZBI)	D	DV	12	2
Gain appraisal	G	DV	5	1

The content and design of the questionnaire was adapted to encourage participants to complete all items by making it as user friendly and as brief as possible in order to maximise recruitment and minimise missing data. A sans-serif type and alternating shaded backgrounds were used to help distinguish neighbouring items from each other more easily. After consulting with local male carers, the wording of some items was also changed so that words relating to the person with dementia were replaced with 'wife/partner'.

2.2.3.1 Caregiver and Care Receiver characteristics. Section A collected information about the caregiver, such as age, years of education and a self-rating of health. The second section, B, recorded the length of marriage/cohabitation, for how long dementia had been suspected, the amount of support used by the couple and the number of services they used.

2.2.3.2 Memory and Behaviour Problems. Kramer (1997b) concluded that memory and behaviour problems displayed by the care-receiver contributed a significant main effect to caregiver strain. Consequently the Revised Memory and Behaviour Problems Checklist (Terri, et al., 1992) was used in Section F of the questionnaire. The RMBPC is a 24-item caregiver report measure of observable behavioural problems and the caregiver's reaction to these. The internal consistency of the RMBPC has been reported by Roth et al. (2003): Total problems $\alpha = .78$; Total carer's reaction $\alpha = .87$.

2.2.3.3 Gender Identity. Section C of the questionnaire comprised the short form of the Personal Attributes Questionnaire (PAQ; Spence & Helmreich, 1978). The PAQ was designed to assess how people view themselves on traditional masculine/instrumental and feminine/expressive traits. The items use a five-point Likert-scale response on 8 items on each of the questionnaire's three scales. Factor analysis supports the validity of the masculine/instrumental (M), feminine/expressive (F), and masculine-feminine (m-f, or

‘androgyny’) scales (Helmreich, Spence & Wilhelm, 1981).

Eight items on the M scale measure characteristics that are socially desirable for both sexes but are considered to be generally more representative of men, such as competitiveness, self-reliance, and assertiveness, and can be summarised as ‘instrumental’. The eight items on the F scale present items typically associated with women such as devotion to others and warmth and are associated with ‘expressiveness’. For the current study, the m-f scale was not used for two reasons. The first was due to the need to keep the questionnaire as brief as possible, and secondly, the m-f scale is conceptually distinct from the other two scales, has the lowest Cronbach’s alpha (.75), and is rarely operationalised or reported in many studies (McCreary & Steinberg, 1992).

The PAQ has been reported to have Cronbach’s alphas of .85, and .82 for the M/I and F/E sub-scales respectively (Spence & Helmreich, 1978; Wilson & Cook, 1984). Test-retest reliability is approximately .06 over a 2.5 month period (Yoder, Rice, Adams, Priest, & Prince, 1982). There have been several studies describing the construct validity of the PAQ (Schichman & Cooper, 1984; Stevens, Pfof, & Ackerman, 1984; Whitley, 1983). Spence and Helmreich (1978) have shown that the PAQ preserves its validity across various socio-economic and age groups.

2.2.3.4 Gender Role Conflict. Section E of the questionnaire consisted of an adapted version of the 37-item Gender Role Conflict Scale (GRCS) (O’Neil, Helms, Gable, David & Wrightsman, 1986). The standard GRCS was originally designed to assess patterns of gender role conflict in men originating in a fear of femininity. The scale is a self-report measure using a six-point Likert scale ranging from *strongly disagree* (1) to *strongly agree* (6). O’Neil and colleagues (1986) described a four factor structure in their factor analysis of the scale. These factors are: (a) Success, Power, Competition ($\alpha = .85$), (b) Restrictive Emotionality ($\alpha = .82$), (c) Restricted Affectionate Behaviour Between Men ($\alpha = .83$), and (d) Conflict Between Work and Family Relations ($\alpha = .75$). Higher scores on the GRCS

indicate more gender-role conflict and greater fear of femininity.

The GRCS was adapted for the current study as some of the questions were identified by some participants as not relevant to men who were likely to be over working age. Some men found that statements related to the fourth factor, Conflict Between Work and Family Relations, irrelevant to their current situation. The CBWFR factor was therefore not included in this study. This also coincides with Gold et al.'s (1995) recommendation that it should be omitted from studies if the research is to take a conservative approach to using the GRCS.

The five items with the highest loading on each factor were included in the adapted version of the GRCS used in this study. Each item was discussed with a pilot group of male carers over the age of 65 and substitutions were made for some of the original GRCS items that were considered irrelevant to men caring for wives with dementia. The Table below indicates the original items and their factor loadings from the GRCS that were used in the current study.

Table 4: The constructs, original item numbers and factor loadings from the Gender Role Conflict Scale (O'Neil, et al., 1986) used in the adapted GRCS in the present study.

GRCS Factor	GRCS item numbers	Factor loading
Success, Power, & Competition	12, 23, 24, 28, 34	.54, .58, .57, .72, .61
Restrictive Emotionality	2, 13, 19, 25, 29	.70, .52, .76, .41, .43
Restrictive Affectionate Behaviour Between Men	7, 10, 16, 20, 33	.69, .58, .67, .71, .66

2.2.3.5 *Appraisals of Burden/Strain*. Section D of the questionnaire consisted of the 12-item Brief Zarit Burden Interview (B-ZBI; Bédard, et al., 2001). The internal consistency of the brief version is reported as ($\alpha = .85$), and is comparable to the full version ($\alpha = .90$) (O'Rourke & Tuokko, 2003). The brief version preserves the two distinct

factors of Personal Strain and Role Strain from the full 22-item instrument, with acceptable indices of internal consistency ($\alpha = .88$ and $\alpha = .78$, respectfully). Role Strain pertains to the demands of the caregiving role, operationalised through responses to items such ‘Do you feel that you don’t have enough privacy as you would like because of your wife/partner?’. Personal Strain refers to the caregiver’s sense of adequacy about being a carer through statements such as ‘Do you feel uncertain about what to do about your wife/partner?’. The response scale uses a five-point Likert rating from 0 to 4. Higher scores on the scale indicate higher perceived burden. After consultation with local male carers, the wording in the items used in the current study varied slightly from the original version in that the terms ‘relative was replaced by the phrase ‘wife/partner’.

2.2.3.6 Appraisals of Gain. The final section, G, of the questionnaire consisted of items relating to perceptions of Gain. Its inclusion was ordered to conclude the questionnaire with a positive outcome measure. There are few standardised measures of Gain widely available (Rapp & Chao, 2000). The measure used in this study consisted of five items taken from the unpublished Caregiving Satisfaction Scale (Strawbridge, 1991, cited in Kramer, 1997a, 1997b). The five items use a five-point Likert scale, 1-Disagree to 5-Agree, which are summed to provide a total scores ranging from 5 to 25. Higher scores indicate more perceived Gain. Measures of the Caregiving Satisfaction Scale’s reliability are not given, but this was assessed during the collection of data in the current study.

2.2.4 Research Procedure

Local NHS and voluntary services for dementia carers were contacted and asked to invite male carers fulfilling the criteria for participating in the study. The inclusion criteria specified that potential participants should be husbands caring for their wives who have a diagnosis of a dementia, or men caring for their life-partner who has a diagnosis of a dementia. Men who considered themselves as principle carers despite their wife or partner

living in residential care were also included in the study. The principal exclusion criteria were that neither the carer nor the care-recipient be experiencing any major complicating health issue.

The participants were given information about the research and asked permission for their names and address to be forwarded to the lead researcher (see Appendix 3). The participants were then posted a questionnaire, a consent form, a postage-paid return envelope, and a £5 voucher to acknowledge their participation in the study (see Appendix 4).

Participants were also recruited through the internet. The questionnaire was converted to a format enabling the collection of participants' responses by clicking on appropriate answers on a web page. The lead researcher joined internet discussion bulletin boards run by the Alzheimer's Society (UK) and the Alzheimer's Association (USA), and invited men caring for their wives and partners to participate in the research. Every effort was made to answer any questions the participants may have had about the research was available to them on the first screen of the website address.

Table 5: Recruitment protocol used in the study.

Local Recruitment	Internet Recruitment
<p>1) Health Service staff teams, Social Services teams, Voluntary Sector teams contacted to help recruit potential participants.</p>	<p>1) Researcher seeks permission to recruit potential participants from moderators of web-based discussion boards.</p>
<p>2) Potential participants identified by known worker from service, given introductory letter and participant information sheet. If agreeable, asked permission for contact details to be passed to researcher.</p>	<p>2) Message posted on board introducing researcher and research. Request for participants made and the web URL at University of Leicester is given. Full contact details and information about the research is also made available.</p>
<p>3) Envelope containing personal introductory letter, participant information sheet, consent form, £5 voucher, return envelope and questionnaire posted to the participant.</p>	<p>3) Participants read information about research, contact details and consent information on web page before completing questionnaire.</p>
<p>4) Participant completes questionnaire, and optional feedback and returns with signed consent form.</p>	<p>4) Participant is offered debriefing information via a web-page and opportunity to provide feedback on the questionnaire.</p>

Standards for internet research were followed in the design of the web-based

questionnaire (Reips, 2002; Kraut et al., 2004). This included providing information about the research and contact details for the researcher (and supervisors) and the University. Ethical considerations for internet research were also followed ensuring preservation of informed consent with anonymity, and offering a level of debriefing (Kraut et al., 2004). To preserve the integrity of the data collection, procedures were taken to prevent repeated submissions (Reips, 2002).

2.2.5 Ethical Approval

Ethical approval was sought and granted from Nottingham Research and Ethics Committee 1. The relevant letters and information can be found in Appendix 5.

2.3 Results

2.3.1 Descriptive data

In the current study, the mean age of the carers and duration of caregiving was broadly representative of other studies (Kramer, 1997b). Just over half the sample (53.9%) cared for their wife or partner on their own without any assistance, and over half used only one service or less (51.4%). The low use of help and support is representative of other studies (Lutzky & Knight, 1994; Stone, Cafferata & Sangl, 1987). A full breakdown of the number and types of services used by the sample is shown in Appendix 6.

Table 6: Demographic variables describing the sample (N = 70).

	Mean (SD)	Range
Age (years)	68.6 (9.7)	43 - 83
Length of marriage (years)	42.9 (13.2)	5 - 62
Duration of caregiving (years)	5.6 (3.9)	1 - 24
Number of helpers	1.0 (1.6)	0 - 9
Number of different services used	1.5 (1.2)	0 - 5

Table 7: Frequency breakdown of number of helpers and services used (N = 70).

Number of helpers		Number of services used	
0	37 (52.9%)	0	17 (24.3%)
1	13 (18.6%)	1	19 (27.1%)
2	9 (12.9%)	2	20 (28.6%)
3	4 (5.7%)	3	11 (15.7%)
4	2 (2.9%)	4	2 (2.9%)
5	2 (2.9%)	5	1 (1.4%)
9	1 (1.4%)		

The demographic spread of education in the current sample was similar to that of other studies on male caregivers (Bowers, 1999; Kramer, 1997b). There were differences in the educational background of the two samples, with the sample recruited from the internet having a higher level of education. A full breakdown and comparison of the two samples is described in Appendix 7.

Table 8: Frequency breakdown of years of education (N = 70).

Education	
Left at age 14	11 (15.7%)
Left at age 15/16	21 (30.0%)
Left at age 17/18	15 (21.4%)
University	12 (17.1%)
Postgraduate	10 (14.3%)

Table 9: Frequency breakdown of self-rating of health (N = 70).

Health	
Poor	4 (5.7%)
Not good	13 (18.6%)
Average	22 (31.4%)
Good	24 (34.3%)
Excellent	7 (10.0%)

2.3.2 Reliability of the Measures

To assess the reliability of the measures used in the questionnaire, Cronbach alphas were computed for the MBPC, PAQ, GRCS, ZBI scales and the five questions comprising the Gain measure.

Table 10: Cronbach alphas of the scales used.

Scale	Cronbach Alpha
<i>Memory and Behaviour Problem Checklist</i>	
Total Score	$\alpha = .90$
Carer's Reaction Total score	$\alpha = .93$
<i>Personal Attributes Questionnaire</i>	
Masculinity/Instrumental	$\alpha = .77$
Femininity/Expressiveness	$\alpha = .74$
<i>Gender Role Conflict Scale</i>	
Success, Power and Competition	$\alpha = .70$
Restrictive Emotionality	$\alpha = .67$
Restrictive Affectionate Behaviour Between Men	$\alpha = .89$
<i>Zarit Burden Interview</i>	
Role Strain	$\alpha = .86$
Personal Strain	$\alpha = .75$
<i>Gain</i>	$\alpha = .84$

All of the Cronbach alphas were over .70, except for the GRCS subscale of Restrictive Emotionality, showing an acceptable level of reliability (Kline, 1999). It is important to note that the GRCS sub-scales were adapted specifically for this study along with the scale measuring Gain. Despite the items in these scales not being subject to a full factor analysis, the Cronbach alphas were of an acceptable standard.

2.3.3 Inter-correlations of variables

Due to the number of independent variables and a limited sample size, it was necessary to keep the number of variables entered into the regression analyses to a minimum. A complete correlation matrix of all the variables used in the study is shown in Appendix 8.

It was decided to use the carer's reaction to the memory and behaviour problems, rather than the total score from the MBPC as a measure referring to the source of stress for the caregivers. It has been shown that this is more directly related to strain and depression than objective measures of dementia such as activities of daily living (ADLs; Zanetti et al., 1998; Kramer, 1997b). The carer's reaction is also more strongly related to strain, as indicated in the correlation matrix, and so would be a more appropriate choice for a predictor variable in a regression analysis.

Only the variables that had a significant relationship with the dependent variables were used for the subsequent multiple regression analyses. The following measures were thus omitted from further analysis: age, duration of marriage, number of services used, and GRCS Restrictive Emotionality. The correlation matrix of the remaining variables are shown in Table 11 below.

Table 11 : Intercorrelations of Independent and Dependent variables used in the regression analyses (N = 70)

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1 Years education	--											
2 Number of helpers	.104	--										
3 Self-rated health	.304**	.171	--									
4 Duration of caring	.031	.079	-.014	--								
5 Carers' Reaction to MBPC	-.138	.138	-.398***	-.009	--							
6 PAQ - M/Instrumentality	.114	-.277*	.145	-.131	-.186	--						
7 PAQ - F/Expressiveness	-.060	.082	.164	-.166	-.302**	.327**	--					
8 GRCS - SPC	-.119	-.058	.055	.006	.159	.148	-.168	--				
9 GRCS - RABBM	-.292**	.084	-.034	.121	.047	-.015	-.089	.252*	--			
10 Role Strain	.015	.211*	-.214*	.208*	.517***	-.274*	-.125	-.104	-.189	--		
11 Personal Strain	-.072	.136	.009	.208*	.441**	-.261*	-.251*	.023	.214*	.614*	--	
12 Gain	-.247*	-.021	.087	.024	-.056	.163	.166	.269*	.404**	-.146	-.071	--

* $p < .05$; ** $p < .01$; *** $p < .001$

The correlation matrix was checked for any independent variables that were highly correlated with one another to reduce collinearity in the regression analyses. Although the two PAQ variables and the two remaining GRCS variables displayed a significant positive correlation with each other, the strength of the relationship was not strong enough to produce any confounding collinearity. (Measures of tolerance and variance inflation factors for all variables used in the multiple regression analyses are shown in Appendix 9).

Three hierarchical regression analyses were carried out on each of the appraisal outcomes of Role Strain, Personal Strain and Gain, to address the three Hypotheses.

2.3.4 Hypothesis 1

Gender Identity and Gender Role Conflict will contribute significantly to appraisals of Role Strain in comparison with known predictors, such as memory and behaviour problems and duration of caregiving.

The known predictors of strain, based on Kramer's (1997b) study, were entered into the regression analysis first. Caregiver characteristics were entered in at step one, and caregiving situation characteristics at step two. The Gender Identity variables were entered in at step three, and the Gender Role Conflict variables at step four. There were no threats to the integrity of the regression due to multicollinearity. On analysing the residuals for outliers, two participants' data for the Role Strain regression, and one participant's data for the Personal Strain regression, were deleted from the final analyses (see Appendix 9).

Table 12: Hierarchical multiple regression predicting Role Strain among husband caregivers (N = 68)

	Betas			
	Step 1	Step 2	Step 3	Step 4
<i>Caregiver Characteristics</i>				
Self rating of health	-.183	.000	.035	.054
<i>Caregiving Situation Characteristics</i>				
Number of helpers		.108	.037	.055
Duration of caring		.213*	.211†	.235*
Reaction to Memory & Behaviour Problems		.504***	.516***	.534***
<i>Gender Identity</i>				
M/Instrumentality			-.200†	-.157
F/Expressiveness			.079	.008
<i>Gender Role Conflict</i>				
Success, Power and Competition				-.129
Restrictive Affectionate Behaviour Between Men				-.269**
Total R^2	.033	.325	.355	.456
R^2 change	.033	.291	.030	.101
F for R^2 change	2.277	9.056***	1.454	5.482**
Total F	2.277	7.570***	5.604***	6.191***

† $p < .10$; * $p < .05$; ** $p < .01$; *** $p < .001$

The regression equation reflected Kramer's (1997b) finding that carers' reaction to the memory and behaviour problems and the duration of caring are strong predictors of Role Strain in husband caregivers. The addition of the measures of Gender Identity and gender conflict increased the amount of variance accounted for in Role Strain by 13.1%, raising R^2 from .325 to .456. However, the increase in total R^2 was significant only for the addition of the Gender Role Conflict measure of restrictive affectionate behaviour between men.

Importantly, the RABBM measure contributed a significant and unique source of variance to the regression model. This lends some support to the Hypothesis. The relationship between the variables was negative, meaning that the more traditionally a man responded to ideas about being emotionally close to other men, the less strain they reported in relation to the demands of caregiving.

2.3.5 Hypothesis 2

Gender Identity and Gender Role Conflict will contribute significantly to appraisals of Personal Strain in comparison with known predictors, such as memory and behaviour problems and duration of caregiving.

The independent variables were entered into a hierarchical regression analysis in the same order as above to determine their relationship with Personal Strain. There were no threats to the integrity of the regression due to multicollinearity. One participant's data strongly affected the regression model as an outlier and so was deleted from the analysis (see Appendix 9). Table 13 below shows the results of the hierarchical multiple regression analysis.

Table 13: Hierarchical multiple regression predicting Personal Strain among husband caregivers (N = 69)

	Betas			
	Step 1	Step 2	Step 3	Step 4
<i>Caregiver Characteristics</i>				
Self rating of health	.018	.208†	.236*	.265*
<i>Caregiving Situation Characteristics</i>				
Number of helpers		.153	.112	.101
Duration of caring		.248*	.223*	.204*
Reaction to Memory & Behaviour Problems		.511***	.487***	.517***
<i>Gender Identity</i>				
M/Instrumentality			-.166	-.148
F/Expressiveness			-.032	-.038
<i>Gender Role Conflict</i>				
Success, Power and Competition				-.147
Restrictive Affectionate Behaviour Between Men				.220*
Total R^2	.000	.328	.356	.407
R^2 change	.000	.328	.028	.051
F for R^2 change	.022	10.404***	1.359	2.588†
Total F	.022	7.811***	5.718***	5.155***

† $p < .10$; * $p < .05$; ** $p < .01$; *** $p < .001$

The multiple regression predicting Personal Strain produced similar results to Role Strain. Again, the carers' reaction to the memory and behaviour problems of their partner was by far the strongest predictor of Personal Strain accounting for a significantly high proportion of the variance in the dependent variable. Self-rating of health and duration of caregiving also contributed to Personal Strain, but to a lesser, although still significant, extent.

Again, both sets of gender variables added some increase in the predictive value of

the regression equation, raising the R^2 from .328 to .407, but the increases in step three and four did not reach significance. The GRCS measure of RABBM was the only gender variable to contribute a significant and unique source of variance to the regression. Interestingly, the direction of the relationship between the RABBM measure and the appraisals of Personal Strain was positive, in contrast to its negative relationship with Role Strain. RABBM accounts for part of the variance in men's appraisals of strain due to feelings of inadequacy about the demands of caring for a wife or partner with dementia.

2.3.6 Hypothesis 3

Gender Identity and Gender Role Conflict will contribute significantly to appraisals of Gain in comparison to known predictors, such as length of education.

Previous research has identified length of education, health, satisfaction with social participation, and problem-focused coping contributing significantly to the amount of variance in measures of Gain (Kramer, 1997b). In the present study, only years of education and a self-rating of health were recorded. Health was not entered into the regression analysis because of its weak non-significant relationship with Gain. The same was also true of all the remaining caregiver situation variables, meaning that the hierarchical regression would be a three-step model. Years of education was entered into the multiple regression at step one. The Gender Identity variables were entered in at step two, and finally the Gender Role Conflict variables at step three.

There were no threats to the integrity of the regression due to multicollinearity. One participant's data strongly affected the regression model as an outlier and so was deleted from the analysis (see Appendix 9). Table 14 below shows the results of the hierarchical multiple regression analysis.

Table 14: Hierarchical multiple regression predicting Gain among husband caregivers (N = 69)

	Betas		
	Step 1	Step 2	Step 3
<i>Caregiver Characteristics</i>			
Education	-.237 [†]	-.249*	-.086
<i>Gender Identity</i>			
M/Instrumentality		.171	.095
F/Expressiveness		.111	.224 [†]
<i>Gender Role Conflict</i>			
Success, Power and Competition			.228*
Restrictive Affectionate Behaviour Between Men			.375**
Total R^2	.056	.110	.302
R^2 change	.056	.054	.192
F for R^2 change	3.931 [†]	1.937	8.542**
Total F	3.931 [†]	2.639 [†]	5.373***

[†] $p < .10$; * $p < .05$; ** $p < .01$; *** $p < .001$

The final regression equation explained 30.2% of the total variance in the appraisals of Gain to a high level of significance. The addition of the Gender Identity variables increased R^2 by a small but non-significant amount. However, in step 3, both the GRC measures added a significant increase in the prediction of variance in appraisals of Gain. It was not until these variables were entered into the regression hierarchy that the model reached significance.

Both the SPC and RABBM variables account for the largest proportion of variance in the final regression equation at 19.2%. Its relationship with appraisal of Gain was positive, meaning that the more Gain a man reported as a result of caring, the more traditional were his responses to being emotionally close to other men and about success, power and competition.

One can conclude that Gender Identity, as measured by the PAQ, does not have an important association with appraisals of Gain. However, both the GRC constructs of SPC and RABBM had a significant positive association with Gain.

2.4 Discussion

The current study focused on whether Gender Identity and Gender Role Conflict are important factors involved in the appraisal of strain and Gain in men caring for wives with dementia. The Hypotheses addressed the general question of whether Gender Identity and Gender Role Conflict could be considered significant predictors of Strain and Gain in comparison to established predictors. The study offered varying levels of support to the Hypotheses. In the following sections, the results of the analyses involving Gender Identity are discussed first before moving on to a discussion of Gender Role Conflict.

2.4.1 Gender Identity

The Gender Identity measures, using the PAQ's scales of masculinity/instrumentality and femininity/expressiveness, do not seem to be important in determining male caregivers' appraisals of strain or Gain in comparison to the other variables assessed in this study. The correlation matrix of all the variables used in this study suggested that both m/instrumentality and f/expressiveness were significantly negatively related to Personal Strain; m/instrumentality was also significantly negatively related to Role Strain. However, neither were associated with the appraisals of Gain made by the caregivers.

The level of significance in the correlation matrix can only be taken as an initial indicator of a possible relationship, as no account of how the other variables in the matrix were associated with the outcome variables could be made by purely observing the bivariate correlations. Any Bonferroni adjustment to the level of significance of the correlations of the PAQ measures would undoubtedly have rendered them non-significant. This was reflected in the hierarchical regression analyses where the PAQ measures did not contribute significantly to the models.

There was an expectation that Gender Identity may have been an important determinant in men making positive and negative appraisals of their caregiving, given the suggestion that instrumental coping has been related to positive affect in caregiving (Rose,

Strauss, & Neundorfer, 1997; Saad et al., 1995), and masculine/instrumental identity has been associated with positive affect in male caregivers who were later widowed (Bowers, 1999). However, in the present study no relationship between either sub-scale of the PAQ was related to any of the outcome measures. It may be that for older men in the caregiving role, their gender identity is not important in how they adapt to becoming a male spouse caregiver and deal with the difficulties the role entails.

2.4.2 Gender Role Conflict

Of the Gender Role Conflict measures, Restrictive Emotionality (RE) did not significantly correlate with any of the Strain or Gain measures, and was therefore not used in any of the regression analyses. This was surprising given the number of studies suggesting that restrictive emotionality is significantly negatively related to self-esteem (Cournoyer, 1994), and also with intimacy when combined with Restrictive Affectionate Behaviour Between Men (RABBM) (Cournoyer, 1994; Sharpe, 1993). Along with the other GRC scale constructs, RE has been shown to be significantly positively associated with anxiety and depression (Cournoyer, 1994; Sharpe & Heppner, 1991), strain or stress (Stillson, et al., 1991), and negatively with help-seeking (Good et al., 1989; Berger, et al., 2005). Although, not all studies describe a clear relationship between RE and negative outcomes, one might expect RE to be related positively to caregiver strain and negatively to caregiver gain. However, no relationship was evident in the present study.

The GRC scale construct of Success, Power and Competition (SPC) also did not contribute significantly to any of the regression analyses of Role Strain or Personal Strain. However, SPC displayed a significant unique relationship with Gain, secondary to the stronger source of variance from RABBM. It was expected that SPC might be important in the husbands' appraisals of caregiving as it has been defined as a pattern of beliefs connected with worries about achievement, competence and failure, dominance and establishing one's superiority in a given situation (O'Neil, 1995). It has also been shown to

be negatively associated with intimacy (Sharpe & Heppner, 1991) and seeking help (Robertson & Fitzgerald, 1992). However, the current regression analyses showed that SPC was not an important factor in male caregivers' appraisals of Strain, but it had a significant positive relationship with Gain.

In contrast to all the gender variables, the GRC scale construct of RABBM was unique in its relationship with the outcome variables. The RABBM measure accounted for a significantly unique amount of variance in every hierarchical regression analyses with the strain and Gain variables. The relationship between RABBM and the Strain measures are discussed first before exploring its relationship with SPC in the regression on Gain.

2.4.2.1 Gender Role Conflict and Strain. RABBM contributed small but significantly unique amounts of variance to the appraisal of both Role Strain and Personal Strain. This influence was secondary to the carers' reactions to the memory and behaviour problems of their partner in both appraisals of strain. This is not surprising, as common sense might anticipate that dealing with the demands of caring for a spouse with a neuro-degenerative disease is the most important source of strain. However, the regression analyses revealed that some of the appraised strain may be determined uniquely by RABBM.

The relationship between RABBM and the two factors of Zarit's measure of strain was different. RABBM was related negatively with Role Strain but positively with Personal Strain. One might predict these both to be positive relationship given the literature describing how RABBM is linked with low self-esteem (Sharpe & Heppner, 1991), low levels of intimacy (Sharpe, 1993), and higher levels of anxiety (Sharpe & Heppner, 1991) and depression (Good & Mintz, 1990) and less effective problem solving (Chamberlin, 1994). Gender Role Conflict is often interpreted as a negative outcome of an overly controlled masculinity, and so one might anticipate negative appraisals about caring.

The differential relationship of RABBM with Role Strain and Personal Strain means that the participants who felt most uncomfortable about being emotional with other men,

reported less strain related to the demands of the caregiving role, and more strain related to feelings of being an uncertain or inadequate carer.

2.4.2.2 Gender Role Conflict and Gain. In terms of appraisals of Gain, RABBM was the most important predictor in the regression analysis. The degree of variance provided by both SPC and RABBM exceeded that of all other variables. Thus, these measures of Gender Role Conflict appear to play an important and independent role in explaining appraisals of Gain in older male caregivers. This was a positive relationship that described men's discomfort about being personal or expressing emotions to other men being associated with positive appraisals about being an older male caregiver. This again was unanticipated given the repeated assertions of negative links with traditional masculine roles outlined above. However, the findings in the current study showed that this is not the case.

2.4.3 Possible explanations for the findings

Why would a man holding traditional beliefs about masculinity be reluctant to report Role Strain, and be more likely to report Personal Strain and Gain? An explanation can be found by interpreting the participants' responses as evidence of them managing conflict between their masculine and caring roles. To 'care' for someone has multiple meanings that may be challenging for male caregivers because of the 'feminine' characterisation of care. Men may find it difficult to balance the tension between caring for their loved one and their masculine identity, so that their appraisals of caregiving may be censored through a response bias that operates to balance this tension.

Evidence of a response bias in husbands and wives caring for their partner with dementia has been reported by O'Rourke et al., (1996). They found evidence that a caregiver's description of their relationship with their spouse was significantly related to their appraisals of burden. The more caregivers defensively monitored how they described

their relationship with their spouse, the less burden they reported. O'Rourke et al. (1996) concluded that self-reported burden is not an accurate measure of perceived burden, but should be more accurately considered as the amount of burden that caregivers are willing to report.

If a response bias was operating in the current study, could it explain the pattern of relationships between GRC and the outcome variables? Mahalik et al. (1998) described how traditional beliefs about gender may act as a defence against threats to masculinity. They assessed men's use of defence mechanisms along with Gender Role Conflict and found that Success, Power and Competition (SPC) and Restrictive Affectionate Behaviour Between Men (RABBM) were significantly related to externalising psychological defences such as projection and turning against the object. They also found that RE was related to internalising defences such as intellectualisation and turning against the self. Ihilevic and Gleser (1993) described men as relying on external defences and women tending to use internalising defences. This may explain why in the current study Restricted Emotionality (RE) was found not to be influential in the men's appraisals of caregiving.

Given that men may tend towards externalised defences, how would this explain the relationship of RABBM being positive with Gain and Personal Strain, and negative with Role Strain? Mahalik et al. (1998) suggested that men who report high RABBM are concerned with protecting themselves against the possibility of negative feelings of anxiety or shame connected with being close to other men, such as appearing feminine or homosexual to others. In other words, beliefs about masculinity are involved in men responding in a socially desirable way, when their masculinity is under threat. Caring for a loved one with dementia may present men with situations in which their masculinity is threatened and in conflict with their expectations of themselves as men. A model of how this may explain the findings in this current study is shown below in Figure 2.

For some older male carers with traditional masculine beliefs, reporting that they feel inadequate and uncertain about the caregiving may be a way of asserting themselves as

Masculinity

Gender Role Conflict: Beliefs about traditional masculinity.

a) Restricted affectionate behaviour between men:

- *Being personal with other men makes me feel uncomfortable.*
- *Expressing my emotions to other men is risky.*
- *Men who touch other men make me feel uncomfortable.*

b) Success, power & competition.

- Competing with others is the best way to succeed.
- I strive to be more successful than others.
- Being smarter and physically stronger than other men is important to me.

Defence

e.g. I can't tell people it is too hard – they will think I can't do it. I can do it, even though it is difficult. Put a brave face on it, and I'll struggle through.

e.g. I'm not very good at being a carer, I don't always know what to do. It's what women do, isn't it? If I was good at this, Would I be more like a woman, less of a man?

e.g. I've not done this before, it is new and I'm learning how to be a better carer, and a better person. I will strive to be a better carer/husband/partner.

Caregiving Strain / Gain

-VE

Under-report **Role Strain:** feeling stressed due to the difficulties of caring.

+VE

Over-report **Personal Strain:** feelings of inadequacy or uncertainty about caring.

+VE

Over-report **Gain:** Positive changes in self as a consequence of caring.

Figure 2: Model of how men caring for their wives/partners with dementia, may appraise role strain, personal strain and gain as a consequence of a socially desirable response bias related to their beliefs about masculinity.

masculine and not woman-like. They may believe that caring is women's work, or that women do it better than men. If they believe this, then they may feel it is acceptable, or even desirable, to say they feel inadequate as a carer and hence report high Personal Strain. Paradoxically, these same men may also feel that saying that they can't cope with caregiving would affect the way people view them, that they are weak, or not man enough for the job (even though it is a woman's job!). This would lead these men to under-report strain when questioned about the demands of the role, as in the Role Strain measure used in the current study.

For, Gain, where SPC is involved as well as RABBM, some men may appraise caregiving as a chance for them to strive to be better as a carer or person, to improve themselves, and so will tend to report more Gain than men with less traditional views about masculinity. An alternative explanation is that men with less traditional beliefs may have experienced dealing with domestic and caring situations before, and so will not necessarily appraise Gain because they are not experiencing anything new about themselves. In contrast, men with more traditional beliefs may never have directly experienced domestic and care situations before and be surprisingly positive about how they have adapted.

2.4.4 Clinical Implications

The findings of the current study suggest that, at least for older husband caregivers, traditional beliefs about masculinity, are important factors to consider when addressing caregivers' appraisals of strain and Gain. Indeed, for Gain, attitudes about how a man accommodates the role of carer with his sense of masculinity is, perhaps, one of the most important determinants. These observations should be noted and incorporated into the support and interventions offered to men carers.

Male caregivers with traditional beliefs about masculinity, are more likely to under-report Role Strain, and more likely to report Personal Strain. They are also more likely to appraise gains from their caregiving role. They are characteristically more likely to say that

(a) they are not feeling burdened, (b) they feel inadequate or uncertain about caring, and (c) they are more likely to think of some positive aspects to being a spousal carer than men with less traditional beliefs about masculinity.

Being aware that some men will under-report strain, due to balancing the roles of carer with his masculinity, will be an important characteristic to assess in offering support to husband carers. Likewise, it may be important to understand that when a man says he is uncertain and inadequate as a carer, this does not mean that he is a bad carer. Care is often seen in 'feminine' terms, and the subjective experience of gender is important in understanding how different men appraise themselves as carers. It will also undoubtedly be involved in how they appraise the services offered and may explain why many men are reluctant to use them.

2.4.5 The limitations of the study

The current study was cross-sectional and therefore the explanations offered for the link between Gender Role Conflict and the participants' appraisals are speculative. It is possible that appraisals of strain or Gain may influence how male carers cope or perceive memory and behaviour problems, as well as how they see themselves in terms of traditional notions of masculinity, instrumentality and expressiveness. A longitudinal study should clarify the process and relationship between the variables.

The sample used in the current study may not have been representative of the population of male carers of partners with dementia. Recruiting through the internet and through local health and social services was used in an attempt to reach men who typically do not use services and those who do. But this strategy was not employed systematically, and may not represent the proportions or variance representative of the male carer population.

A further limitation of the study is reflected in the use of some measures that may not have been sensitive to the concerns of older male caregivers. The Gender Role Conflict

Scale had to be adapted for use with older men, but this was done without any further analysis of the adapted measures' factor structure. The same criticism could also be made about the PAQ, which was developed using American college students and has been shown to lack some validity in British populations (McCreary & Steinberg, 1992). In addition, an improved and more detailed measure of positive appraisal may offer more understanding about gain in caregiving.

2.4.6 Future Research

The explanation offered here for the relationship between male carers' appraisals and Gender Role Conflict, suggests further questions about how responses to spousal care may be mediated by socially desirable response biases. The explanation is hypothetical, but offers testable hypotheses about husband and older male-partner carers. Comparisons of men holding different beliefs about gender could be made on objective measures of burden as well as subjective ones. A few studies have assessed caregiver stress using hormonal, neurotransmitter, immunologic, antibody, cardiovascular, and metabolic indicators of stress (see Vitaliano, Scanlan & Zhang, 2003, for a review).

If Gender Role Conflict is an important factor that may determine older male caregivers' attitudes and behaviours, then it will impact on aspects of their lives other than the appraisals of Strain and Gain covered in this study. Gender Role Conflict has been shown to be negatively associated with help-seeking behaviours (Berger et al., 2005) and social support (Hill & Donatelle, 2005). It is also an important factor in considering how to engage men in programmes that encourage them to look after themselves both physically and psychologically (see Addis & Mahalik, 2003 for a review). Researching the impact of Gender Role Conflict on male carers' use of informal and formal support would be an important and fruitful endeavour.

For some time, several authors in dementia care have been asserting the need to investigate the variation in carers' responses to dementia caregiving (Vitaliano, Scanlan &

Zhang, 2003). The present study is an example of how this can be done by using a sub-sample of carers, specifically older husbands and male partners, and addressing aspects of their personal characteristics that may be relevant to their appraisals of being a caregiver, such as masculinity. The same approach could be taken with other significant sub-groups of carers such as younger husbands/male partners, wives/female partners, and sibling and offspring carers.

2.4.7 Conclusion

In conclusion, the current study was guided by the idea that aspects of Gender Identity and Gender Role Conflict may be important in considering the appraisals of Strain and Gain men may make of caring for a wife or partner with dementia. The regression analyses showed that Gender Identity, as measured by the PAQ, did not predict any of the negative or positive appraisals of caregiving. However, traditional masculine values were important in these men's appraisals of Strain and Gain to varying degrees. The relationship between these constructs is not straightforward, and may represent a complex process that deserves further investigation. This could contribute to the development of services and interventions that could be more successful in engaging and supporting older male caregivers.

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3.0 Critical Reflection

3.1 Origins of the study

The current study on male caregivers stemmed from a long standing interest in issues related to masculinity. I combined this interest with my clinical experience of working with men caring for their wives while working in an integrated mental health team for older people. A number of the husband carers I worked with coped very well with the difficulties of caring both physically and emotionally for their wives. Many said that there would be no other option for them but to give their wives as much care as they possibly could. They spoke of their marriage vows and their sense of duty, and often referred to the fact that their wives had looked after them and their children for so many years, and that now it was their turn to take on the responsibility of care.

Some of the husbands I met used the carers' groups run by a CMHT and by local branches of the Alzheimer's Society. I attended some meetings and was struck by the variety of experiences and personalities, but behind this I was sensitive to the possibilities of how men may think about themselves as carers and as men. I guessed that many men over the age of 65 had not experienced many of the tasks they had now taken on for the first time, because their wives were functionally disabled by the progress of dementia. However, there were also vast differences amongst the men. Some men told me that they had always done the shopping and cleaning, and that for them the difficulties of caring for their wife were purely emotional. Others remarked that they found everything difficult, and that it was much easier for women. One husband told me:

“If you are a woman carer, you can ask a neighbour to fix a shelf or door and usually a man will gladly come and do it. But as a man, it is very difficult to ask a neighbour to help cook a dinner or wash some clothes. You partly feel a bit stupid for having to ask, and you also know that not many female neighbours think about helping you anyway.”

These observations helped me to formulate how men may experience the difficulties of caring in a different way from most women. For women there is an expectation that they will continue to care because they have always done it. But for men, there may need to be a

period of transition and adaption to the role, especially if they have never been involved in domestic tasks connected with familial care. Both women and men may experience problems in dealing with the demands and strain associated with caring, but the formulations of their problems may be different and based on their gendered experiences.

I was also struck by how nursing and social-work colleagues saw many of the husband carers and how they worked with them. Health and Social care seemed to me to be oriented around a feminised idea of care that almost excludes men, or at least expects men not to be very good at it. Most of my colleagues in the teams were women, as most nurses and social workers are. In the U.K., 81% of the workforce in Health and social care are women (Office for National Statistics, 2001). Care and support is often spoken about in terms of reducing anxiety and increasing confidence in the carer. In themselves, these appear to be non-problematic, but they are often dealt with through affective or verbal ways. Or, in other words, ways characteristic of a 'feminine' approach.

Indeed, many of the husbands I met judged themselves to be not very good carers. One said, "I am too rough. I don't have the patience that the nurses and helpers have." For this husband, and many others, comparing how he looked after his wife with the way that the female nurses and home helps did, resulted in negative self-appraisals.

After reflecting on these observations in supervision and in discussions with some of the husband carers I worked with, I began to explore the literature on men carers. I soon found that there was not very much written about older men in general, let alone the sub-group of older men carers. This piqued my interest even further. I came across two groups of American academics whose work has helped in developing my ideas. One group was psychologists who had been studying men and masculinity for some time. These included James O'Neil, Ronald Levant, Joseph Pleck and William Pollack. Their ideas have formed the basis for some of my thoughts on the importance of gender in dementia care (Levant & Pollack, 1995; Pollack & Levant, 1998). The other group of academics was a mix of

sociologists and social workers who have focused their work on older men. They included Betty Kramer and Edward Thompson. (Kramer, 1993, 1997, 2000; Kramer & Thompson, 2002; Thompson, 1994). Through reading and discussing the ideas in both these collections of writers I was able to develop the current study.

3.2 Development of the study

Initially, an interview approach to investigating husband carers seemed the most obvious. It felt as though this would be the only way to get to ‘understand’ these men. I was aware of the difficulties of interview-based research and had never used qualitative methods in a large study before. In addition, my previous experience of talking to researchers, reading qualitative research, and knowing that there was limited supervision available, steered me away from taking a qualitative approach. On further reflection, it may also have been my own sense of masculinity that pushed me away from the language-based, collaborative and undetermined nature of interview and qualitative methods. In contrast, quantitative methods and statistical analysis, appeared more attractive. I was aware of the ‘masculine’ nature of this approach with its associations of independence, expertise, knowledge and certainty. These weren’t attributes that I wanted to affect the way I did the research. I wasn’t satisfied with acknowledging these characteristics of traditional quantitative methods and began to think of ways of working differently within a quantitative methodology. It soon became apparent that simply by not following the sex-difference paradigm, the research could focus on exploring male carers’ masculinities in more depth, even when using a quantitative method. This critique became central to the literature review of sex-difference paradigm research.

For a long time I was attracted to using Repertory Grids and Personal Construct Psychology. I had been introduced to this approach on placement and had used grids clinically. I spent some time searching for someone with experience of supervising trainees in using rep-grids. But later, I decided to take the more traditional route of using a

questionnaire survey method. In part, this was also heavily influenced by an idea to further Kramer's (1997) study on husband caregivers by adding an assessment of masculinity to her regression analyses.

One of the problems with Kramer's (1997) interpretation of her findings is that it may be considered sexist in its assumptions about men. To explain why men with more education are less likely to report gain, she drew on the assumption that these men were more likely to have worked as upper managers in more prestigious jobs. She further suggested that these men may consequently be less likely to appraise gain in caregiving than less educated husbands, and be less able to find the daily tasks of caregiving rewarding because they may consider caring an activity that is below them. Such an explanation may seem plausible, but rests on an assumption about men that is unrelated to the context of caring for a wife. I doubted that any of the husband caregivers I worked with would agree with Kramer's thesis. Nearly every husband I worked with had demonstrated that they were dedicated to their wife's care, and most took pride in the 'work' that they did in their caregiving. The assumption that an educated man would not appraise caregiver gain, felt as if Kramer missed the importance of most husbands' dedication to their wives and marriage vows. This is one reason why I felt that a replication of Kramer's research with the addition of assessing masculinity would be important. (An alternative explanation to Kramer's based on the current study's findings is described in the conclusion to the research report).

The next problem I struggled with was the questionnaire itself. At first, it seemed straightforward to replicate Kramer's study and simply add in the PAQ and GRCS. However, this would mean that the questionnaire would be much too long. After completing the literature review, using a coping measure also looked a little more complicated than I had originally thought. The problems with operationalising coping and the length of many of the established questionnaires made it difficult to decide on how to

progress with this problem. I have written in more detail about the decision not to use coping in the research in Appendix 2. So I decided to proceed without an assessment of coping.

At this point, reflecting on the nature of the investigation that was taking shape, I often felt that I had made the wrong decision. I felt that simply entering in data from questionnaires may miss some important aspect of masculinity and caregiving. I decided to put more emphasis on opening up the research process and engaged in as much contact with participants as they wanted. Most participants did not contact me to ask any questions. But a few were intrigued and entered into email correspondence with me.

In addition to making myself open to enquiries, I went further to include an option to offer the participants the chance to be interviewed at a later date about the research. The intention was to attempt a validity check on the findings from the questionnaire. Unfortunately, I did not have the time or resources to follow this through before handing in the thesis, but it has given me the chance to extend the research, check the findings and continue investigating the issues involved in men caring for their wives or partners with dementia.

3.3 Data collection

Data collection proceeded fairly smoothly at first. I made several visits to Community Mental Health Teams (CMHTs), day hospitals and day centres run by both the NHS and Social Services. I found this a little exhausting as many of the contacts I made were understandably busy in their work. I attempted to strengthen my relationship with the contacts I had made but this was difficult when I only worked one day a week in the service. This was compounded further by me breaking my shoulder in January, with the consequence of not being able to drive for almost two months. I spent this time finishing off the web-based questionnaire, and started recruiting participants through internet discussion lists for carers of people with dementia.

There was a contrast with the contacts I had made through the voluntary sector and those through the NHS and Social Services. The managers and workers in organisations such as the Alzheimer's Society, Trent Crossroads, and Age Concern were enthusiastically helpful in distributing information about my study and recruiting possible participants. This was by far the easiest route for recruitment.

Collecting data through the internet was very efficient. All that was needed was to check a secure web page to view the complete data set and copy it into a spreadsheet. There was no need to input any data or to worry about inputting errors. In contrast, collecting data locally meant some delay in postage. I posted the questionnaires to the carers after they consented to participate via a nurse, social worker or voluntary worker. I then had to wait for the questionnaire to be returned to me via the University.

3.4 Feeding back

I had anticipated the need to feedback to participants and organisations involved in my research from the start. In contacting the local Alzheimer's Society, Age Concern and Trent Crossroads, I offered to give them a summary of the research once it was completed. In addition, I have also made a summary available to the participants, both locally and through the internet discussion forums.

In the middle of collecting data, I was contacted by a journalist working for the Alzheimer's Society who had heard about my research through the discussion forum, and was interested in writing a piece for their in-house magazine. This also made me think about different levels of dissemination than the traditional journal article and conference presentation that is expected from NHS research. I contacted the *Journal of Dementia Care* and spoke to the editors about submitting a review article and a research report about my study. The *Journal of Dementia Care* is a multi-disciplinary journal aimed at all professionals working with people with dementia. This would enable my findings to reach a wider audience than psychologists reading academic journals.

I also arranged to present my research and findings to some local health professionals before handing in the thesis. Although this put some pressure on me to complete the data collection and analysis ahead of time, it also forced me to consider what ‘story’ the research should tell and to think about what its central points were. I presented to some colleagues in a Community Learning Disability Team, and discussed how my research was applicable to working with older male carers of adult children with learning disabilities. There appeared to be many similarities and I hope to one day investigate this further. I also presented to psychiatrists, psychologists and researchers working in psychiatry of the elderly in a local trust research group.

These presentations have helped me to focus on the important aspects of the research and findings. It has been difficult to determine the ‘take home message’, partly because it is so often difficult to think about masculinity and to explain it. The presentations enabled discussions about the findings and also the chance for discussions about male caregivers known to the audience. In July, I am presenting the research to the National PSIGE conference.

3.5 Writing up

Writing the literature review seemed fairly straightforward in comparison to the research report. With the review I managed to condense much of the information because within the context of gender and masculinity, most of the research reviewed did not seem to be helpful in understanding how to work with male carers. This was aided by discussing the basic findings of the literature on sex differences, and some of the qualitative research (e.g. Harris, 1993, 1995) with other psychologists, nurses and social workers, as well as some husband carers.

The experience of writing up the research report was qualitatively different. Once I had collected enough data to analyse the results, I then had to work out how to explain them. This was difficult for a number of reasons. First, I became acutely aware of the

limitations of the research, especially as I read more widely around the subject areas of masculinity and dementia care. I discuss more of this below. Secondly, I did not leave enough time to discuss the findings in detail with a number of people. I would have liked to have spent more time discussing how I have explained the results with more psychologists and with more male carers, before writing up the thesis.

Thirdly, and lastly, as I was writing up, I felt that the report could be better written as two shorter research reports rather than one long one. The report was complicated to write with explanations needed about the distinctions between Gender Identity and Gender Role Conflict, along with distinctions between Role Strain, Personal Strain, and Gain. I considered a few different ways of reporting the research, but this took up a lot of time, and eventually I may have ended up with something of a compromise. The report is long in order to cover the many different variables that seem to be important because they have rarely been covered in the literature.

3.6 Critique of the research

There are several more limitations to the study than those mentioned in the Discussion of the Research Report. First, the limitation about recording the background characteristics of the sample is discussed, followed by the limitations referring to the measures used.

The participants recruited for the current study were not asked about their racial or cultural background. It is known that this is an important factor in caregiver burden and coping. Along with gender, the cultural, racial and ethnic background of the carer shape the caregiving experience and have implications for interventions and services (Adams, Aranda, Kemp & Takagi, 2002; Connell, Janevic, & Gallant, 2001). Although the majority of the carers in the local sample were white and English, no information was recorded for the internet sample. This could be a confounding factor in the analyses. It has been shown that caregiver gain is appraised differently in African-American carers when compared to

Americans from other ethnic background (Adams et al., 2002).

In addition to cultural background, sexuality was not explicitly explored in the current study. In order not to be excluding, the sexuality of the participant was not asked for. However, there may be differences in the adaptation and appraisal that gay men make to the caring role related to social comparisons and discrimination leading to differential attitudes to the use of social support and formal services.

The local recruitment of participants was carried out through support groups and services. Although, some were users of services, the majority did not use services to support them in caring for their wives or partners (see Appendix 6). The local recruitment was mostly opportunity sampling and was possibly biased. This is a common limitation of caregiver research, with a dependency on recruiting through care-support services and agencies. But the internet recruiting attracted significantly more participants who did not use services. There were not enough numbers to include this difference as an analysis in the current study, but it may be possible to continue recruiting participants until ethical approval runs out. Although the two sampling methods may have confounded the sample in that it was not homogenous (see Appendix 7), it may have been more representative of male carers in general. It is known that over half of male carers do not use services in the U.S.A. (Stone, Cafferata & Sangl, 1987), and that the majority of carers in the UK do not use services (Twigg, 1992). Future research could continue with this recruiting method to improve sampling.

The measures employed in the study were also a source of further limitations to the study. Some of the measures were adapted from existing measures: The Gender Role Conflict scale was developed using cohorts of American college students. In piloting the study with a group of husband carers, it was found that an adapted version was necessary because a large number of the original items were thought to be irrelevant to British men over working age. Given the growing importance of older men as spousal and family carers, a standardised and relevant Gender Role Conflict scale for older British men would

be an important improvement. In addition, McCreary and Steinberg (1992) have found the construct validity and factor structure of the PAQ to be questionable when used on a British non-student sample. This may explain why the PAQ did not show any strong association with any of the outcome variables in this study.

The measure of Gain appraisals in the present study was also an adaptation as no standardised measure was available. Although, the Cronbach alpha of .84 demonstrated that the measure had a high level of internal reliability, this is not an indication of its validity.

In the current study a short form of the Zarit Burden Interview (ZBI) was used in an effort to reduce the length of the questionnaire and fatigue in the participants. However, the original 22-item ZBI was criticised by Knight, Fox, and Chou (2000) who suggested that a three-factor structure better describes carers' appraisals of strain in terms of embarrassment/anger, patient's dependency, and self criticism. This structure offers more detail than the traditional two factors of Role Strain and Personal Strain in understanding the caregivers' negative appraisals. This detail may lead to improved interpretations of the measures co-varying with burden such as coping and gender role conflict. Knight, Fox and Chou (2000) also noted that there was a wide discrepancy in the way caregiver burden is operationalised between research in applied settings and theoretical research. Applied researchers tend to use a singular measure of burden (most frequently based on the ZBI), while researchers interested in the theoretical nature of burden use more multi-dimensional measures.

3.7 Summary: Reflecting on the whole

Reflecting on the whole process of carrying out this literature review and research, it has certainly been a memorable experience! I have been able to have conversations with a wide range of people that have reminded me of the privileges of being a psychologist. It is not every day that one gets to converse with a husband who has been married for 71 years

and loves his wife so much that it now makes him cry, because although she is physically fitter than he is, she has Alzheimer's disease and he fears that she will be taken away from him. In comparison, my most difficult task was trying to make sense of everything that I thought ought to be included in the research and this thesis. But if this could help develop sensitive support to someone like this 92 year old man, it would be worth it. Knowing this, helped with the single mindedness I needed to repeatedly discuss and re-write.

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Appendices

Appendix 1: Instructions to authors: The Gerontologist, Aging and Mental Health.

THE GERONTOLOGIST

General Information and Instructions to Authors

(Revised October 2004)

The Gerontologist is a bimonthly journal of The Gerontological Society of America that provides a multidisciplinary perspective on human aging through the publication of research and analysis in gerontology, including social policy, program development, and service delivery. It reflects and informs the broad community of disciplines and professions involved in understanding the aging process and providing service to older people. Articles, including those in applied research, should report concepts and research findings, with implications for policy or practice. Contributions from social and psychological sciences, biomedical and health sciences, political science and public policy, economics, education, law, and the humanities are welcome. Brief descriptions of innovative practices and programs are appropriate in the Practice Concepts section.

1. Submission and Acceptance of Manuscripts

Authors are strongly encouraged to submit all manuscripts online at <http://tg.allentrack.net>.

Prior to submission, corresponding authors should gather the following information: (a) complete contact information for themselves and each contributing author; at a minimum, this should include mailing address, e-mail address and phone number; (b) a copy of the manuscript, in a Word-compatible format, including title page, key words, acknowledgements, abstract, text, and references; DO NOT BLIND the manuscript for online submissions. If the manuscript is selected for peer review, it will be blinded by TG staff; (c) a separate file for each table (in Word or Excel) and each figure (most common graphics formats are acceptable; figures also may be embedded in a Word-compatible file, though this is not recommended); (d) a cover letter (optional) explaining how the manuscript is innovative, provocative, timely, and of interest to a broad audience, and other information authors wish to share with editors. Note: The cover letter for new manuscripts will NOT be shared with reviewers.

For multi-author papers, the journal editors will assume that all the authors have been involved with the work and have approved the manuscript and agree to its submission. (If the manuscript is eventually accepted, all authors will be required to certify that this is the case.)

Additional instructions regarding web-based submissions appear online.

If there is a compelling reason why the author cannot submit online, submissions will be accepted via e-mail to tg@benrose.org. If a manuscript is submitted through the mail (to Linda S. Noecker, Editor-in-Chief, The Gerontologist, Benjamin Rose, 850 Euclid Avenue, Suite 1100, Cleveland, OH 44114-3301), the submission MUST include both a hard copy of the manuscript and an electronic version on disk.

2. Acceptance of Manuscripts

Submission of a manuscript to *The Gerontologist* implies that it has not been published or is not under consideration elsewhere. If accepted for this journal, it is not to be published elsewhere without permission. As a further condition of publication, the corresponding author will be responsible, where appropriate, for certifying that permission has been received to use copyrighted instruments or software employed in the research and that human or animal subjects approval has been obtained.

In the case of coauthored manuscripts, the corresponding author will also be responsible for submitting a letter, signed by all authors, indicating that they actively participated in the collaborative work leading to the publication and agree to be listed as an author on the paper. These assurances will be requested at the time a paper has been formally accepted for publication.

3. Manuscript Preparation

The *Gerontologist* uses APA style. General guidelines follow; for more detailed information, consult the *Publication Manual of the American Psychological Association* (5th ed.).

- Preparing the manuscript. Manuscripts should be double-spaced, including references and tables, on 8-1/2" x 11" white paper using 1" margins. Number pages consecutively for the abstract, text, references, tables, and figures (in this order).
- Submitting the manuscript. Manuscripts should be submitted online at <http://tg.allentrack.net>. (See above for details).
- Title page. The page should include complete contact information for each author, including (at a minimum) affiliation, mailing address, e-mail address, and phone number. Corresponding author should be clearly designated as such.
- Acknowledgement. If the authors choose to include acknowledgements recognizing funders or other individuals, these should be placed on a separate page immediately following the title page. These will be removed from the manuscript when it is blinded for review.
- Abstract and key words. On a separate page, each manuscript must include a brief abstract, double-spaced. Abstracts for research articles and Practice Concepts submissions should be approximately 200 words (the web-based system will not accept an abstract of more than 250 words), and must include the following headings: *Purpose* of the study, *Design and Methods*, *Results*, and *Implications*. Forum manuscripts must also include an abstract of about 200 words, but the headings are not necessary. Brief reports should include a brief abstract (25 to 50 words). Below the abstract, authors should supply 3-5 key words that are not in the title. (Please avoid elders, older adults, or other words that would apply to all manuscripts submitted to TG.) Please note you may not move forward in the online submission process until a minimum of 3 key words have been entered.
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When a reference has more than 2 authors and fewer than 6 authors, cite all authors the first time the reference occurs. In subsequent citations, and for all citations having 6 or more authors, include only the surname of the first author followed by "et al." Multiple references cited at the same point in the text are in alphabetical order by author's surname.

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Examples:

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Books: Quadagno, J. S. (1982). *Aging in early industrial societies*. New York: Academic Press.

- Tables. Prepare tables, double-spaced in separate files, number consecutively with Arabic numbers and supply a brief title for each. Place table footnotes immediately below the table, using superscript letters (a, b, c) as reference marks. Asterisks are used only for probability levels of tests of significance ($p < .05$). Indicate preferred placement for each table in the text.
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- Research Articles.** Most articles present the results of original research. These manuscripts may be no longer than 6,000 words. The text is usually divided into sections with the headings: Introduction, Design and Methods, Results, and Discussion. Subheads may also be needed to clarify content.
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- Practice Concepts.** Practice Concepts are manuscripts of no more than 4,000 words that critically review the state-of-the-art in a major area of professional practice OR describe an innovative practice amenable to replication. Authors reporting on practice innovations should clearly specify the following information about the practice: uniqueness or innovativeness, theoretical or conceptual basis, essential components or features, lessons learned from implementation, and data concerning outcomes. An important goal is to provide enough information about the practice to allow its replication by readers.
- Letters to the Editor.** Letters related to content in recent issues are published as space permits. Letters should be no more than 900 words, double-spaced. Letters are subject to review, editing, and rebuttal.
- Book Reviews.** Book reviews are published in essay form. Reviews are prepared at the request of the Book Review Editor and are not guaranteed acceptance prior to submission. Unsolicited book review essays are not accepted. Books for review should be sent to Robert H. Binstock, PhD, Book Review Editor, Professor of Aging, Health, and Society, School of Medicine, Case Western Reserve University, Cleveland, OH 44106.
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All submissions should be in the style of the **Publication Manual** of the American Psychological Association (4th edition, 1994). Papers should be typed on one side of the paper, double spaced throughout (including the references), with margins of at least 2.5 cm (1 inch). All pages must be numbered.

The first page should include the title of the paper, first name, middle initial(s) and last name of the author(s), and for each author a short institutional address, and an abbreviated title (for running headlines within the article). At the bottom of the page give the full name and address (including telephone and fax numbers and e-mail address if possible) of the author to whom all correspondence (including proofs) should be sent. The second page should repeat the title and contain an **abstract of not more than 200 words**. The third page should repeat the title as a heading to the main body of the text.

Structured abstracts: The main text should be preceded by a short structured abstract, accompanied by a list of keywords. The abstract should be arranged as follows: Name of author(s); title of manuscript; name of journal; abstract text containing the following headings: Objectives, Method, Results, and Conclusion.

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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. Within the text section headings and subheadings should be typed on a separate line without numbering, indentation or bold or italic typeface.

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We prefer email submissions only - in Microsoft Word format. Do not save your files as "text only" or "read only".

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References should follow APA style. All publications cited in the text should be listed following the text; all references listed must be mentioned in the text. Within the text references should be denoted by the author's name and year of publication in parentheses, e.g. (Woods, 1995) or (Mansell & McGill, 1995) or, if there are more than two authors, (Gallico *et al.*, 1986). Where several references are quoted consecutively within the text the order should be alphabetical, e.g. (Elford & Sherr, 1989; Folkman, 1992). Similarly, where several references are quoted within a single year, the order should be alphabetical (Mansell & McGill, 1995; Woods, 1995). If more than one paper from the same author(s) and year is listed, the date should be followed by (a), (b) etc., e.g. (Blazer, 1995a).

References should be listed at the end of the paper in alphabetical order, typed in double spacing. Responsibility for the references and their verification against the original documents lies with the author(s).

References should be listed on a separate sheet(s) in the following standard form, capitalisation and punctuation:

a) for periodical articles (titles of journals should not be abbreviated):

WOODS, B. (1995). Dementia care: progress and prospects. *Journal of Mental Health*, 5, 115-124.

b) for books:

NORMAN, A. (1987). *Aspects of ageism*. London: Centre for Policy on Ageing.

c) for chapters within multi-authored books:

ROBERTSON, I. T. (1994). Personality and personnel selection. In C. L. COOPER & D. M. ROUSSEAU (Eds.), *Trends in organizational behavior* (pp. 75-89). Chichester: Wiley.

Units of measurement

All measurements must be cited in SI units.

Illustrations

All illustrations (including photographs, graphs and diagrams) should be referred to as Figures and their position indicated in the text (e.g. Fig. 3). Each should be submitted on a separate sheet of paper, numbered on the back with Figure number (Arabic numerals) and the title of the paper. The captions of all figures should be submitted on a separate sheet, should include keys to symbols, and should make interpretation possible without reference to the text.

Figures should ideally be professionally drawn and designed with the format of the journal (A4 portrait, 297 x 210 mm) in mind and should be capable of reduction.

Tables

Tables should be submitted on separate sheets, numbered in Arabic numerals, and their position indicated in the text (e.g. Table 1). Each table should have a short, self-explanatory title. Vertical rules should not be used to separate columns. Units should appear in parentheses in the column heading but not in the body of the table. Any explanatory notes should be given as a footnote at the bottom of the table.

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Appendix 2: Explanation of why a coping measure was not used.

The literature review in this thesis, set out to explore the research focused on men coping with caring for a wife with dementia. Coping was intentionally incorporated into the review of papers, so that any findings could be set within a theoretical framework that could be used to inform interventions or support services. However, very little research was found that operationalised coping on a sample of male caregivers within such a framework. Kramer's (1997) study was the only one to use a "stress – resource – appraisal" framework on a sample of husband caregivers. A similar approach was taken with the current study but no measures of coping were used for the following reasons.

In reviewing how coping may be operationalised it became apparent that this is often problematic for many researchers. Carradice, Beail and Shankland (2003), in their review of caregiver intervention research, concluded that the variety of ways in which coping is measured makes it difficult to compare the results across studies. This variation also suggests that coping is sometimes used as a general measure rather than the specific, context-dependent construct described by Lazarus and Folkman (1984). Many commentators and reviewers (Matson, 1994; Kneebone & Martin, 2003; Gottlieb & Wolfe, 2002) have maintained that coping measures should be tightly defined by the caregiver situation. So that assessing coping by people caring for someone with dementia should contextualise the questions asked in any interview or questionnaire. This refers to Lazarus and Folkman's (1984) assertion about their process approach to coping: that contextual factors help us understand the link between thoughts/acts and demands, and hence provide findings that may be usable clinically.

In searching for a measure of coping appropriate to carers of people with dementia, there appeared to be two options. One was to use a general coping measure that could be adapted to the carers situation such as Kneebone and Martin's (2003) assessment tool, or

the Ways of Coping Checklist as used by Kramer (1997). However, this relies on an interview approach, or the expectation that participants will spend the time to think and itemise specific instances of the difficulties they may have faced recently in caring for their spouse. Using such an approach may have increased the validity of a measure of coping, but it would also have increased the time needed to complete the questionnaire. Such an approach may also have increased the number of participants dropping out of the study. The other option was to use a short general coping questionnaire, such as the short-form version of the COPE (Carver, 1997). The problems with using a non-situation-specific questionnaire means that the study would be faced with most of the criticisms outline in critical reviews about caregiver coping (Carradice, Beail & Shankland, 2003; Kneebone & Martin, 2003).

For these reasons, many researchers have found it difficult to operationalise coping. Some researchers have often ended up simply employing a coping measure with little thought to the theoretical importance of their research (Matson, 1994; Kneebone & Martin, 2003). Other commentators have observed that many researchers are often tempted to use coping as part of a barrage of measures with the intention of exploration and discovery rather than focusing on testing any hypotheses suggested from a model (Gottlieb & Wolfe, 2002).

As Kramer (1997) has investigated coping in husband caregivers already there is no need to replicate her design entirely in order to assess the influence of gender on outcome appraisals of caregiving. The addition of another independent variable into the regression analyses would also have affected the power and effect size, with the requirement to increase the sample size as a consequence.

The Personal Attributes Questionnaire assesses instrumentality and expressiveness. But these are operationalised as aspects of personal identity not coping behaviours, styles, or traits. The items in the measure are rated by the participant as characteristics they think they possess. The use of the PAQ does not replace a measure of coping, but is an attempt to

investigate the effect of generally accepted gendered personality characteristics, such as identity, on appraisals of caregiving.

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Appendix 3: Contact letters to colleagues and potential participants, contact form and information sheet given to potential participants



Men caring for their wives/partners with dementia.

December, 2005

Dear colleague,

Thank you for helping me recruit participants for my doctoral research. My research is focused on how men care for their wives or partners who have dementia. I am interested in how they feel about being a carer and any connection this may have with their self-identity. I hope that this may later be of some use in developing services to support men carers.

I need to recruit about 100 participants and am asking professionals working with older adults in Nottingham, Leicester and Derby to give information about my research to men carers who may be looking after their wives or long term partners. I am able to give each participant a £5 Boots voucher to thank them for the 20 minutes or so it will take them to complete a postal questionnaire.

If you know of any men caring for their wives or partners with dementia, I would be grateful if you could ask them if they would be interested in participating in my research. I have enclosed an **introductory letter** from me and an **information sheet** that you could leave with the carer. (Please could you write your name as the contact person in the box provided on the information sheet). If the carer agrees to me contacting them about the research, I would be grateful if you could complete the **contact details** and return this to me at the address below. I will then post the carer a consent form, the questionnaire, and a stamped return envelope.

If you have any questions I am more than happy to answer them.

Thank you very much.
Sincerely,

Kevin Baker
Psychologist in Clinical Training

Supervised by Dr. David Connelly
Clinical Psychologist

Sheila Gibson Unit
Bramwell, Chilwell Lane
Nottingham, NG9 3DU
Tel: 0115 907 6127/6200
Email: klb34@le.ac.uk or david.connelly@nottshc.nhs.uk



Men caring for their wives/partners with dementia.

December, 2005

Dear sir,

I am a Psychologist completing my clinical training with the University of Leicester and Nottingham Healthcare NHS Trust. I am carrying out research to find out more about how men care for their wives/partners who are experiencing dementia. I am interested in how this may affect how they feel about caring and how they think about themselves.

Participating in this research is entirely voluntary, but it would be very useful to gain your views as these may help the NHS to improve and develop services. The questionnaire should take about 15-20 minutes to complete. The information you give will be confidential and will only be seen by myself.

Attached to this letter is an information sheet about the research that you should take time to read before deciding to participate in this research. If you feel that you would like more information, please don't hesitate to contact me.

If you would like to participate in this research please tell the person who gave you this letter. They will pass on your contact details to me and I will post you a copy of the questionnaire. We are able to give you a £5 Boots voucher to thank you and reimburse you for your time.

At a later date, I would also like to interview some men carers to discuss the findings of this study and to ask more about their experiences of caring for their wives/partners. If you would be interested in volunteering for this part of the research there will be a consent form with your questionnaire for you to return to me.

Yours Sincerely,

Kevin Baker
Psychologist
University of Leicester

Telephone: 0116 223 1639



Men caring for their wives/partners with dementia:

Contact Details

The following person has agreed to participate in the research study:

Your name (contact person for the participant): _____

Participant's Name: _____

Wife's first name: _____

Address (inc. post code): _____

Telephone: _____

Please return this to Kevin Baker.

Sheila Gibson Unit
Bramwell, Chilwell Lane
Nottingham, NG9 3DU

Tel: 0115 907 6127/6200

Mob: 07788 520 323

Email: klb34@le.ac.uk or david.connelly@nottshc.nhs.uk



Men caring for their wives/partners with dementia

INFORMATION SHEET

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully to help you to decide whether or not you wish to take part. You may want to discuss the study with your wife/partner or some other person. Please ask if there is anything that is not clear or if you would like more information.

Background and purpose of the study

Most of what we know about carers is based on studies that look at women carers. Very little is known about how men care. The aim of this study is to understand more about how men feel about looking after someone with dementia and how this might be related to how they think about themselves.

Why you have been invited to take part?

You have been invited to take part in this study because you have been identified as being a caregiver to your wife/partner. Taking part in the research is entirely voluntary and will not in any way affect the care your wife/partner receives or any services you use. You can withdraw from this study at any time.

Will taking part in the study be kept confidential?

Your GP will be notified that you have consented to take part in the study, but your responses to the questions will be kept completely confidential.

What taking part involves?

The research consists of a questionnaire. Taking part involves ticking or circling responses to the questions and returning the questionnaire in the envelope provided (no stamp is needed). The questionnaire is anonymous and does not ask for any identifying information. To thank you for taking part we have enclosed a £5 Boots voucher with the questionnaire.

In addition to the questionnaire, we would like to interview some men about their experiences of caring and to see if the results of the questionnaire study are relevant to them. This will help check the validity of our findings. This part of the study is optional and voluntary. If you are interested in volunteering to be interviewed, please on the consent form that accompanies the questionnaire. Kevin Baker, the lead researcher for this study will contact you early in 2006 to arrange a time and place convenient to you for this interview.

What are the disadvantages of taking part?

There are no disadvantages of taking part as far as we can see. However, some people may feel that thinking about some of the issues raised by the questionnaire may generate some anxiety. If you feel that you would like to speak someone about this, you can contact either the researcher, Kevin Baker or the Clinical Psychologist supervising this research, Dr. David Connelly. Their contact information is printed overleaf.

Please turn over...



What are the benefits of taking part?

Taking part will mean that we may find out more about how men take care of their wives/partners when they have dementia. This means that the NHS might be able to provide more and better support for some men. The results of the research will be fed back to all of the consultants' teams and day services collaborating in this research. The findings will also be published in professional and academic journals.

Who is funding the study?

The research has been funded by Leicester University.

Who has reviewed the study?

The research has been reviewed and passed by the University of Leicester and the NHS ethics committee for Nottingham.

Who should I contact if I want to find out more or want to make a complaint?

The lead researcher for this research is Kevin Baker. You can contact him about any aspect of this research. The research is jointly supervised by Dr. Noëlle Robertson at the University of Leicester, and Dr. David Connelly at the Sheila Gibson Unit, Nottingham Healthcare NHS Trust. If you have any queries about the research but do not want to talk to Kevin Baker, you can contact either Dr. Robertson or Dr. Connelly.

Contact Information:

Kevin Baker
School of Psychology
University of Leicester
104 Regent Rd,
Leicester, LE1 7LT
Tel: 0116 223 1639
Email: klb34@le.ac.uk

Dr. David Connelly
Clinical Psychologist
Sheila Gibson Unit
Bramwell, Chilwell Lane,
Nottingham, NG9 3DU
Tel: 0115 907 6127
Email: david.connelly@nottshc.nhs.uk

Dr. Noëlle Robertson
Senior Lecturer
School of Psychology
University of Leicester
104 Regent Rd., Leicester, LE1 7LT
Tel: 0116 223 1648
Email: nr6@le.ac.uk

Contact details of the person who gave you this information:

[Empty box for contact details]

Appendix 4: Questionnaire, participant introduction letter, and consent form.



Men caring for their wives/partners with dementia

Participant Code Number: _____

A) About yourself

1) How old are you: _____

2) How many years education did you receive as a young person?(or what age did you leave school or college)

3) How would you rate your own health?

- | | | | | |
|------|----------|---------|------|-----------|
| 1 | 2 | 3 | 4 | 5 |
| poor | not good | average | good | excellent |

B) About you and your wife/partner

1) How long have you been married to your wife / lived with your partner?

2) How long ago was it that you and/or your wife/partner suspected that dementia might be the explanation for any changes you have experienced?

3) How many people, other than yourself, help care for your wife/partner?

4) If your wife/partner uses residential care, please indicate how many days a week?

5) Do either of you use any services like those listed below? (please tick all that apply):

<input type="checkbox"/> Don't use any services	<input type="checkbox"/> Respite care	<input type="checkbox"/> Day Services (Social Services)
<input type="checkbox"/> Day Hospital (NHS/Health)	<input type="checkbox"/> Alzheimer's Society Support Groups	
<input type="checkbox"/> Meals on wheels	<input type="checkbox"/> Residential Care Home (full-time)	<input type="checkbox"/> Carers Support Group
Other (please describe) _____		



C) What kind of person are you?

The items below ask you about what kind of person you think you are. Each item consists of a PAIR of characteristics, with the letters A-E in between. For example,

Not at all artistic A.....B.....C.....D.....E Very artistic

Each pair describes contradictory characteristics - that is, you cannot be both at the same time, such as very artistic and not at all artistic.

The letters form a scale between the two extremes. Please choose a letter that describes where YOU fall on the scale.

For example, if you think that you have no artistic ability, you would choose A. If you think that you are pretty good at art, you might choose D. If you are only medium, you might choose C, and so forth.

1.	I am...	not at all independent	A.....B.....C.....D.....E	very independent
2.	I am...	not at all emotional	A.....B.....C.....D.....E	very emotional
3.	I am...	very passive	A.....B.....C.....D.....E	very active
4.	I am...	not at all able to devote self completely to others	A.....B.....C.....D.....E	able to devote self completely to others
5.	I am...	very rough	A.....B.....C.....D.....E	very gentle
6.	I am...	Not at all helpful to others	A.....B.....C.....D.....E	Very helpful to others
7.	I am...	Not at all competitive	A.....B.....C.....D.....E	Very competitive
8.	I am...	Not at all kind	A.....B.....C.....D.....E	Very kind
9.	I am...	not at all aware of feelings of others	A.....B.....C.....D.....E	very aware of feelings of others
10.	I...	can make decisions easily	A.....B.....C.....D.....E	have difficulty making decisions



11. I...	give up very easily	A.....B.....C.....D.....E	never give up easily
12. I am...	not at all self-confident	A.....B.....C.....D.....E	very self-confident
13. I...	feel very inferior	A.....B.....C.....D.....E	feel very superior
14. I am...	not at all understanding of others	A.....B.....C.....D.....E	very understanding of others
15. I am...	very cold in relations with others	A.....B.....C.....D.....E	very warm in relations with others
16. I...	go to pieces under pressure	A.....B.....C.....D.....E	stand up well under pressure



D) How do you feel about caring?

These questions ask you about how you feel about some of the aspects of caring for your wife/partner.

	Never	Rarely	Sometimes	Quite frequently	Nearly always
1. Do you feel that because of the time you spend with your wife/partner, that you do not have enough time for yourself?	0	1	2	3	4
2. Do you feel stressed between caring for your wife/partner and trying to meet other responsibilities (work/family)?	0	1	2	3	4
3. Do you feel angry when you are around your wife/partner?	0	1	2	3	4
4. Do you feel that your wife/partner currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4
5. Do you feel strained when you are around your wife/partner?	0	1	2	3	4
6. Do you feel that your health has suffered because of your involvement with your wife/partner?	0	1	2	3	4
7. Do you feel that you don't have as much privacy as you would like because of your wife/partner?	0	1	2	3	4
8. Do you feel that your social life has suffered because you are caring for your wife/partner?	0	1	2	3	4
9. Do you feel that you have lost control of your life since your wife's/partner's illness?	0	1	2	3	4
10. Do you feel uncertain about what to do about your wife/partner?	0	1	2	3	4
11. Do you feel you should be doing more for your wife/partner?	0	1	2	3	4
12. Do you feel that you could do a better job in caring for your wife/partner?	0	1	2	3	4
	Never	Rarely	Sometimes	Quite frequently	Nearly always



E) The following statements are about some general feelings you might have about yourself and other men. Please circle the number which most closely represents how much you **Agree** or **Disagree** with each statement. There is no right or wrong answer to each statement; your first reaction is usually the best.

	Strongly Disagree			Strongly Agree		
1. I have difficulty telling others I care about them.	1	2	3	4	5	6
2. Affection with other men makes me tense.	1	2	3	4	5	6
3. Expressing my emotions to other men is risky.	1	2	3	4	5	6
4. I measure other people's value by their level of achievement and success.	1	2	3	4	5	6
5. Talking (about my feelings) during sexual relations is difficult for me.	1	2	3	4	5	6
6. Men who touch other men make me uncomfortable.	1	2	3	4	5	6
7. I have difficulty expressing my tender feelings.	1	2	3	4	5	6
8. Hugging other men is difficult for me.	1	2	3	4	5	6
9. Competing with others is the best way to succeed.	1	2	3	4	5	6
10. Winning is a measure of my value and personal worth.	1	2	3	4	5	6
11. I often have trouble finding words that describe how I am feeling.	1	2	3	4	5	6
12. I strive to be more successful than others.	1	2	3	4	5	6
13. I do not like to show my emotions to other people.	1	2	3	4	5	6
14. Being very personal with other men makes me feel uncomfortable.	1	2	3	4	5	6
15. Being smarter or physically stronger than other men is important to me.	1	2	3	4	5	6
	Strongly Disagree			Strongly Agree		



F) Below is a list of problems people with dementia sometimes experience. Please indicate if your wife/partner experienced any of these problems during the past week. If so, please indicate how much has this bothered or upset you when it happened?

Please use the following scales for the frequency of the problem and to indicate how it has bothered you.

This happened... 0 = never occurred
1 = not in the past week
2 = 1 to 2 times in the past week
3 = 3 to 6 times in the past week
4 = daily or more often
X = don't know/not applicable

This bothers me... 0 = not at all
1 = a little
2 = moderately
3 = very much
4 = extremely
X = don't know/not applicable

	This happened	This bothers me
1) Asking the same question over and over	0 1 2 3 4 X	0 1 2 3 4 X
2) Trouble remembering recent events (e.g. in the newspaper or on TV)	0 1 2 3 4 X	0 1 2 3 4 X
3) Trouble remembering significant past events	0 1 2 3 4 X	0 1 2 3 4 X
4) Losing or misplacing things	0 1 2 3 4 X	0 1 2 3 4 X
5) Forgetting what day it is	0 1 2 3 4 X	0 1 2 3 4 X
6) Starting, but not finishing, things	0 1 2 3 4 X	0 1 2 3 4 X
7) Difficulty concentrating on a task	0 1 2 3 4 X	0 1 2 3 4 X
8) Destroying property	0 1 2 3 4 X	0 1 2 3 4 X
9) Doing things that embarrass you	0 1 2 3 4 X	0 1 2 3 4 X
10) Waking you or other family members at night	0 1 2 3 4 X	0 1 2 3 4 X
11) Talking loudly and rapidly	0 1 2 3 4 X	0 1 2 3 4 X
12) Appears anxious or worried	0 1 2 3 4 X	0 1 2 3 4 X
13) Engaging in behaviour that is potentially dangerous to self or others	0 1 2 3 4 X	0 1 2 3 4 X
14) Threatens to hurt self	0 1 2 3 4 X	0 1 2 3 4 X



This happened... 0 = never occurred
 1 = not in the past week
 2 = 1 to 2 times in the past week
 3 = 3 to 6 times in the past week
 4 = daily or more often
 X = don't know/not applicable

This bothers me... 0 = not at all
 1 = a little
 2 = moderately
 3 = very much
 4 = extremely
 X = don't know/not applicable

	This happened	This bothers me
15) Threatens to hurt others	0 1 2 3 4 X	0 1 2 3 4 X
16) Aggressive to others verbally	0 1 2 3 4 X	0 1 2 3 4 X
17) Expressing feelings of hopelessness or sadness about the future (e.g. "I never do anything right", "Nothing worthwhile ever happens")	0 1 2 3 4 X	0 1 2 3 4 X
18) Crying and tearfulness	0 1 2 3 4 X	0 1 2 3 4 X
19) Commenting about death of self or others (e.g. "Life isn't worth living", "I'd be better off dead")	0 1 2 3 4 X	0 1 2 3 4 X
20) Talking about feeling lonely	0 1 2 3 4 X	0 1 2 3 4 X
21) Comments about feeling worthless or being a burden to others	0 1 2 3 4 X	0 1 2 3 4 X
22) Comments about feeling like a failure or about not having any worthwhile accomplishments in life	0 1 2 3 4 X	0 1 2 3 4 X
23) Arguing, irritability, and/or complaining	0 1 2 3 4 X	0 1 2 3 4 X



6) Finally, these questions ask you about some of the positive feelings you may have about caring for your wife/partner.

	Disagree			Agree	
1. Caring for my wife/partner has helped me to realise that I can do things I never knew that I could do.	1	2	3	4	5
2. Caring for my wife/partner gives me small but important uplifts now and then.	1	2	3	4	5
3. Caring for my wife/partner has boosted my self esteem.	1	2	3	4	5
4. Caring for my wife/partner has made me more aware of my inner strengths.	1	2	3	4	5
5. Caring for my wife/partner has helped me to become more self confident.	1	2	3	4	5

Thank you very much for taking the time to complete this questionnaire.

Your responses will be very valuable.

Please use the envelope supplied to return the questionnaire along with the consent form.

If you have any comments you would like to make about this questionnaire, please write them here:



Men caring for their wives/partners with dementia.

June, 2006

Dear Mr PARTICIPANT,

A short while ago, CONTACT, community nurse from the TEAM, asked you if you would be interested in participating in a research project on men caring for their wives/partners. Thank you for agreeing to participate in this research. Participating in this research is entirely voluntary. Your views will be very useful as they may help the NHS to improve and develop services for dementia care.

I have enclosed an information sheet about the research and a consent form together with the questionnaire. Please take the time to read the information sheet before signing the consent form. If you feel that you would like more information or would like some help in completing the questionnaire, please don't hesitate to contact me.

The questionnaire should take about 15-20 minutes to complete. The information you give will be anonymous and confidential and will only be seen by myself.

Once the questionnaire is completed please return it to me, with the signed consent form, using the stamped addressed envelope. I hope the enclosed £5 Boots voucher will help reimburse you for your time.

At a later date, I would also like to interview some men to discuss the findings of this study and to ask more about their experiences of caring for their wives/partners. If you would be interested in volunteering for this, please indicate on the consent form and return with your questionnaire.

Yours Sincerely,

Kevin Baker
Psychologist
University of Leicester / Nottingham Healthcare NHS Trust
Contact telephone: 0116 223 1639



Men caring for their wives/partners with dementia

Consent form

This is a consent form to say that you understand the research you are kindly volunteering to take part in. Before signing this consent form you should read the accompanying information sheet.

The research consists of answering the questions on the questionnaire. If you are willing to be interviewed about the results of the research at a later date please indicate below.

1. I confirm that I have read and understand the information sheet dated November 2005 (version 2.3) for the above study.

2. I understand that my participation in all parts of the research is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I agree to be interviewed by Kevin Baker about the results of this research at a time and place convenient to me

Name of Participant

Date

Signature

Researcher

Date

Signature

Please return this with your questionnaire in the envelope provided.

Appendix 5: Ethics committee approval letter



Nottingham Research Ethics Committee 1

1 Standard Court
Park Row
Nottingham
NG1 6GN

Telephone: 0115 912 3344 ext 49435
Facsimile: 0115 9123300

28 September 2005

Mr. K Baker
68 Julian Road
Nottingham
NG2 5AN

Dear Mr. Baker

Full title of study: Husbands caring for wives with dementia: masculinity, burden and distress.

REC reference number: 05/Q2403/120

Thank you for your letter of 09 September 2005, 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.

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.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to complete Part C of the application form or to inform Local Research Ethics Committees (LRECs) about the research. However, all researchers and local research collaborators who intend to participate in this study at NHS sites should notify the R&D Department for the relevant care organisation and seek research governance approval

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application		09 September 2005
Investigator CV Mr KL Baker		12 July 2005
Investigator CV Dr N Robertson		12 July 2005
Investigator CV Dr DJ Connelly		12 July 2005

An advisory committee to Trent Strategic Health Authority

Protocol	2.0	01 June 2005
Letter from Sponsor		17 June 2005
Peer Review Dr M Christie		23 June 2005
Peer Review Dr A Reay		20 June 2005
Statistician Comments		01 June 2005
Questionnaire	2.2	09 September 2005
Letter of invitation to participant	1.5	01 June 2005
Participant Information Sheet Husband	2.2	09 September 2005
Participant Information Sheet Partner	2.2	09 September 2005
Participant Consent Form	2.2	09 September 2005
Response to Request for Further Information		09 September 2005
Flowchart of protocol	1.5	01 June 2005

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/Q2403/120

Please quote this number on all correspondence

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

Yours sincerely



Dr K Pointon / Ms L Ellis
Chair / Committee Co-ordinator

Email: jeannie.mckie@rushcliffe-pct.nhs.uk

Enclosures:

Standard approval conditions Site approval form

Copy to:

University of Leicester
104 Regent Rd
Leicester
LE1 7LT
R&D Department for NHS care organisation at lead site – Leicester
Partnership Trust

Appendix 6: Breakdown of number and type of services used.

The questionnaire provided the respondents with the following selections of the types of services that they may be using to help care for their wife. The frequency of each selection is shown in the Table below.

Table 15: Breakdown of type of service used by the participants and their frequency.

Service	Frequency (percentage)
Don't use any services	16 (22.9%)
Respite Care	13 (18.6%)
Day Services (Social Services)	15 (21.4%)
Day Hospital (NHS/Health)	3 (4.3%)
Residential Care Home (Full-time)	6 (8.6%)
Carers' Support Group	26 (37.1%)
Alzheimer's Society Support Group	19 (27.1%)
Meals on Wheels	4 (5.7%)
Other	17 (24.3%)

The services selected as 'Other' were: Crossroads sitters (5); home nursing via health insurance (2); paid caregivers (3); Church based support group (1); Alzheimer's Society outreach worker (1); community nurse visits (1); social services home care (1); Pick's disease support group (1).

Appendix 7: Comparison of the internet-recruited sample and the locally-recruited sample.

Thirty-three participants were recruited through internet bulletin boards and completed the internet version of the questionnaire. The geographic location of the internet sample are shown in Table 16 below. The majority of these participants were located in the U.S.A., although 6 were from the U.K.

Table 16: Frequency breakdown of the geographic location of the internet sample (N = 33).

Location	Frequency
U.S.A.	25
England	5
France	1
New Zealand	1
Wales	1

Thirty-seven participants were recruited locally in the East Midlands through support groups, and Community Mental Health Teams of Older People and returned completed questionnaires by post. A series of two-sample *t*-tests and χ^2 tests were carried out to determine whether the two groups were significantly different on any of the independent and dependent variables. The results of these analyses are shown in Table 17 below.

Importantly, none of the Strain variables, or their known predictors (health, duration of caregiving, memory and behaviour problems), were significantly different for the two samples. This means that the regression analyses and their interpretation for the Strain outcome variables were considered to have been carried out on a homogenous sample.

Table 17: Comparison of demographic, predictor and outcome variables for the two samples used in the study.

Variable	Internet sample (N = 33), mean (SD)	Local sample (N = 37), mean (SD)	<i>t</i> or χ^2
Age	62.2 (8.2)	74.3 (6.9)	<i>t</i> = 6.717***
Length of Marriage	34.0 (13.1)	50.8 (6.5)	<i>t</i> = 6.910***
Duration of caregiving	5.3 (4.6)	5.8 (3.3)	<i>t</i> = .504
Number of helpers	1.1 (1.9)	.9 (1.3)	χ^2 = 2.197
Number of services	.91 (1.1)	2.0 (1.1)	χ^2 = 18.1**
Education	5.6 (1.1)	4.1 (1.0)	χ^2 = 26.4***
Health	3.4 (1.2)	3.1 (.9)	χ^2 = 7.928
Total MBP	40.6 (21.3)	36.1 (15.5)	<i>t</i> = .980
Carer's reaction to MBP	25.4 (18.2)	29.0 (20.0)	<i>t</i> = .774
PAQ m/instrumentality	24.4 (4.6)	24.4 (4.8)	<i>t</i> = .061
PAQ f/expressiveness	23.8 (4.7)	22.7 (3.7)	<i>t</i> = 1.111
GRCS RE	14.2 (4.5)	18.5 (5.0)	<i>t</i> = 3.707***
GRCS SPC	13.3 (4.5)	16.0 (5.9)	<i>t</i> = 2.111*
GRCS RABBM	16.9 (7.2)	23.4 (5.4)	<i>t</i> = 4.193***
Role Strain	16.5 (7.1)	15.7 (6.6)	<i>t</i> = .513
Personal Strain	5.3 (2.7)	5.7 (2.9)	<i>t</i> = .601
Gain	14.3 (2.9)	16.4 (5.0)	<i>t</i> = 2.052*

* $p < .05$; ** $p < .01$; *** $p < .001$

In comparison, the two samples differed significantly on age, length of marriage, number of services used, level of education, all the GRCS variables and Gain. The internet sample was significantly younger ($t(32) = 6.717, p < .001$), and had consequently been married for less time. This can be explained by the obvious strong inter-correlation between age and length of marriage ($r = .852, p < .001$).

The internet sample had a significantly higher number of participants who had longer

education than the locally recruited sample ($\chi^2 = 18.1, p < .01$). This is almost to be expected given that higher education usually leads to more opportunities of using computers and the internet. It is of note that education was significantly correlated to the GRC scale construct of Restrictive Affectionate Behaviour Between Men ($r = -.292, p = .007$) and with Gain ($r = -.247, p = .02$), but not with Restrictive Emotion and Success, Power and Competition.

The observation that the two samples significantly differed on these measures does not threaten the regression analysis on Gain, because the GRCS variables were entered after the education variable, and so any covariance was controlled for. In addition, no collinearity between these variables was noted in the regression statistics (see Appendix 9).

The two samples were also significantly different on the men's use of number of services ($\chi^2 = 18.1, p < .01$). The internet sample accessed less services than the local sample. This might be explained in two ways. The internet sample seemed to rely more on number of helpers, although this was not significantly different from the local sample. In addition, one might expect that the reason a carer was using the internet for support through discussion forums, was because they were not gaining support from local services or groups. Importantly for the regression analyses, number of services was not used as a predictor variable.

Appendix 8: Inter-correlation matrix between all variables used in the study.

The inter-correlation matrix of all variables used in the current study are shown overleaf. Observations on the significant relationships between the variables are outlined below.

Observations on the correlation matrix: Strain

Kramer (1997b) identified that memory and behaviour problems, duration of caregiving, and health were important in accounting for the amount of variance in appraisals of strain in her hierarchical multiple regression. These findings are reflected here in the correlation matrix. However, more detail is available in the present study due to the use of the two factors of Role Strain and Personal Strain.

Duration of caregiving is significantly related to both of the sub-scales of strain (both reporting $r = .208, p = .042$). The longer a man has been caring, the more likely he is to feel strained due to the demands of the caregiver role, and also strained due to his sense of inadequacy. The carers' self-rated health is significantly related to Role Strain in a negative direction ($r = -.214, p = .037$) but not Personal Strain. The better health a man feels the less strained he feels about the demands of caregiving, but this is not associated with his feelings of inadequacy or uncertainty about caregiving.

A novel finding in the present study not accounted for in Kramer's (1997b), was that the number of helpers was significantly positively related to Role Strain ($r = .211, p = .04$) and not Personal Strain. For the men carers in this cohort, the higher the number of people helping him care for his partner, the more strain related to demands of caring were reported, but this had no association with strain related to feelings of adequacy or inadequacy.

Correlations

	AGE	YRSED	SR-HEALTH	YrsMainted	Yrs Dementia	HELPERS	NumServices	RMBPCTotal	GRTOTAL	PAQM	PAGF	GRCS-SPC	GRCSRE	GRCSRABBM	ZBIROLE	ZBIPERS	GAIN
AGE	Pearson Correlation Sig. (1-tailed) N	1 -.346** 70	-.142 .002 69	-.121 .000 70	.852** .000 70	.035 .311 70	.313** .004 70	.097 .213 70	.166 .085 70	-.021 .431 70	-.130 .142 70	.256** .016 70	-.359** .001 70	-.488** .000 70	-.065 .297 70	.083 .248 70	.164 .087 70
YRSED	Pearson Correlation Sig. (1-tailed) N	-.346** 1 69	1 .005 69	-.451** .000 69	.031 .400 69	.104 .197 69	.196 .063 69	.044 .359 69	-.138 .129 69	.114 .312 69	-.060 .312 69	-.119 .166 69	-.189 .060 69	-.292** .007 69	.015 .278 69	-.072 .278 69	-.247** .020 69
SR-HEALTH	Pearson Correlation Sig. (1-tailed) N	-.142 .002 69	1 .005 69	-.189 .068 70	-.014 .455 70	-.171 .079 70	-.061 .309 70	-.408** .000 70	-.398** .000 70	.145 .115 70	.164 .088 70	.055 .324 70	.024 .421 70	-.034 .391 70	-.214* .037 70	.009 .472 70	.087 .237 70
YrsMainted	Pearson Correlation Sig. (1-tailed) N	-.451** .000 69	-.142 .002 69	1 .000 70	.161 .092 70	.052 .334 70	.308** .005 70	.120 .160 70	.247** .020 70	-.065 .298 70	-.154 .102 70	.205* .044 70	.257** .016 70	.408** .000 70	-.012 .460 70	.160 .092 70	.194 .054 70
Yrs Dementia	Pearson Correlation Sig. (1-tailed) N	-.014 .031 70	-.014 .400 69	.161 .092 70	1 .000 70	.121 .257 70	.158 .011 70	.113 .472 70	-.131 .141 70	-.166 .085 70	-.131 .085 70	.006 .479 70	.142 .120 70	.121 .159 70	.208* .042 70	.208* .042 70	.024 .421 70
HELPERS	Pearson Correlation Sig. (1-tailed) N	.035 .197 69	.171 .079 69	.052 .334 70	.079 .257 70	1 .000 70	.121 .158 70	.117 .126 70	-.277** .010 70	.082 .251 70	.082 .251 70	-.058 .316 70	-.047 .350 70	.084 .244 70	.211* .040 70	.136 .131 70	-.021 .431 70
NumServices	Pearson Correlation Sig. (1-tailed) N	-.196 .053 69	-.061 .308** 69	.308** .005 69	.272** .011 70	.121 .158 70	1 .327 70	-.054 .327 70	-.039 .374 70	.103 .197 70	.105 .193 70	.123 .155 70	.113 .175 70	.130 .141 70	.023 .427 70	.055 .327 70	.186 .062 70
RMBPCTotal	Pearson Correlation Sig. (1-tailed) N	.097 .213 70	.044 .359 69	-.120 .160 70	.120 .160 70	.117 .168 70	.064 .327 70	1 .785** 70	.138 .127 70	-.277** .010 70	-.148 .126 70	.110 .183 70	-.028 .410 70	-.090 .230 70	.502** .000 70	.304** .005 70	-.055 .327 70
GRTOTAL	Pearson Correlation Sig. (1-tailed) N	-.138 .123 69	-.398** .000 69	-.398** .000 69	.247** .020 69	.138 .127 70	.374 .000 70	.785** .000 70	1 .000 70	-.186 .251 70	-.302** .006 70	-.159 .094 70	.123 .155 70	.047 .349 70	.517** .000 70	.441** .000 70	-.056 .321 70
PAQM	Pearson Correlation Sig. (1-tailed) N	-.021 .431 70	.145 .115 69	-.065 .205* 69	-.131 .479 70	.117 .168 70	.103 .197 70	-.139 .126 70	-.186 .061 70	.327** .003 70	.327** .003 70	.148 .111 70	-.093 .221 70	-.015 .451 70	-.274* .011 70	-.261* .014 70	.163 .088 70
PAGF	Pearson Correlation Sig. (1-tailed) N	-.130 .142 70	-.060 .312 69	-.154 .088 69	-.154 .102 69	.082 .251 69	.105 .193 69	-.054 .327 69	-.039 .374 69	.103 .197 69	.105 .193 69	-.168 .082 69	-.182 .066 69	-.089 .232 69	-.125 .151 69	-.251* .018 69	.166 .084 69
GRCS-SPC	Pearson Correlation Sig. (1-tailed) N	.256** .016 70	.119 .166 69	.205* .044 69	.034 .421 69	.055 .324 69	.024 .421 69	.024 .421 69	.024 .421 69	.182 .066 69	.182 .066 69	1 .182 69	.182 .066 69	.252* .018 69	-.104 .196 69	.023 .426 69	.269* .012 69
GRCSRE	Pearson Correlation Sig. (1-tailed) N	.359** .001 69	.189 .060 69	.408** .000 69	.042 .391 69	.079 .309 69	.309 .000 69	.000 .000 69	.000 .000 69	.115 .088 69	.088 .088 69	.324 .066 69	.421 .066 69	.391 .232 69	.037 .151 69	.472 .018 69	.237 .084 69
GRCSRABBM	Pearson Correlation Sig. (1-tailed) N	-.488** .000 69	-.292** .007 69	-.408** .000 69	.042 .391 69	.079 .309 69	.309 .000 69	.000 .000 69	.000 .000 69	.115 .088 69	.088 .088 69	.324 .066 69	.421 .066 69	.391 .232 69	.037 .151 69	.472 .018 69	.237 .084 69
ZBIROLE	Pearson Correlation Sig. (1-tailed) N	-.065 .297 69	.015 .451 69	-.214* .037 69	-.042 .460 69	.040 .237 69	.023 .427 69	.502** .000 69	.517** .000 69	-.274* .011 69	-.125 .151 69	-.104 .196 69	-.147 .113 69	-.189 .059 69	1 .000 69	.614** .000 69	-.146 .114 69
ZBIPERS	Pearson Correlation Sig. (1-tailed) N	.083 .248 69	-.072 .278 69	.160 .092 69	.208* .472 69	.136 .131 69	.055 .327 69	.304** .005 69	.441** .000 69	-.261* .014 69	-.251* .018 69	.023 .426 69	.137 .128 69	.137 .128 69	.614** .000 69	1 .280 69	.071 .280 69
GAIN	Pearson Correlation Sig. (1-tailed) N	.164 .087 69	.087 .237 69	.194 .064 69	.024 .421 69	-.021 .431 69	.186 .062 69	-.055 .327 69	-.056 .321 69	.163 .088 69	.166 .084 69	.269* .012 69	.122 .157 69	.404** .000 69	-.146 .114 69	.071 .280 69	1 .000 69

**, Correlation is significant at the 0.01 level (1-tailed).

*. Correlation is significant at the 0.05 level (1-tailed).

Observations on the Correlation Matrix: Gain

Kramer's (1997b) hierarchical multiple regression on appraisals of Gain, found that education, health, satisfaction with social participation and problem-focused coping were significant predictors. In the present study only years of education and a self-rating of health was recorded. Again, the correlation matrix of the variables used in the present study reflects Kramer's findings with years education being significantly negatively related to Gain ($r = -.247, p = .02$). The more education a man has had the less Gain he will self report. In the present study, health was unrelated to appraisals of Gain. In the present study, the carers' self-rating of health was not significantly related to Gain.

Observations on the correlation matrix: Gender Identity

The two sub-scales of the PAQ were significantly related to measures of strain. The F/Expressive scale was significantly negatively related to Personal Strain ($r = -.251, p = .018$) only, while the M/Instrumental scale was significantly negatively related to both factors of strain ($r = -.274, p = .011$, for Role Strain, and $r = -.261, p = .014$ for Personal Strain). The fact that these are negatively related means that the more expressive a man identifies himself as the less Personal Strain he reports, and the more instrumental he reports himself to be, the less personal and Role Strain he reports. These results lend some support to the idea that an androgynous identity (high instrumental and high expressive identity) leads to a more adaptive problem solving style (REFERENCE). This is more fully explored in the analysis of variance for the PAQ categories in Appendix 10. Interestingly, the measures of Gender Identity were not significantly related to appraisals of Gain.

Observations of the correlation matrix: Gender Role Conflict

The two sub-scales of the GRC scale showed varying levels of relationship with appraisals of strain and Gain. None of the GRC scale variables displayed a significant

relationship with Role Strain, although Restrictive Affectionate Behaviour Between Men is approaching significance ($r = -.189, p = .059$). Whereas RABBM is positively related to Personal Strain ($r = .214, p = .038$). Both Success, Power and Competition and RABBM are significantly positively related to Gain ($r = .269, p = .012$, and $r = .404, p < .001$, respectively). The relationships between the GRC constructs are more fully explained in the hierarchical regression analyses reported in the main body of the research report.

Appendix 9: Hierarchical regression statistics for the three dependent variables: Including measures to assess normal distribution of residuals, Cook's D for outliers, residual scatterplots for homoscedascity and linearity, and measures of collinearity.

In order to satisfy the assumptions of regression analysis, the data set was checked for its normal distribution. Participants' data was excluded from the analysis if it had an extreme effect on the residuals and dependent variable. Procedures for making these decisions was based on those reported in Tabachnik and Fidell (2001), and Miles and Shevlin (2001).

For each regression analysis, the independent variables were first entered into the regression analysis to check the normal distribution of the standardised residuals. Measures of skewness and kurtosis were used to assess the normal distribution. The Table below indicates that the standardised residuals for both sets of independent variables can be assumed to be normally distributed.

Table 18: Standardised residuals statistics for the independent and dependent variables used in each hierarchical regression analysis.

Standardised residual	Mean	SD	Skewness	SE	Kurtosis	SE
Role Strain	.0000000	.94024357	-.109	.287	-.394	.566
Personal Strain	.0000000	.94024357	-.286	.287	.305	.566
Gain	-.0156016	.96126703	-.028	.289	.037	.570

Next the residuals were checked for the effect of outliers on the independent and dependent variables using Cook's D. Box-plots indicating the spread of Cook's D statistics were examined for extreme values.

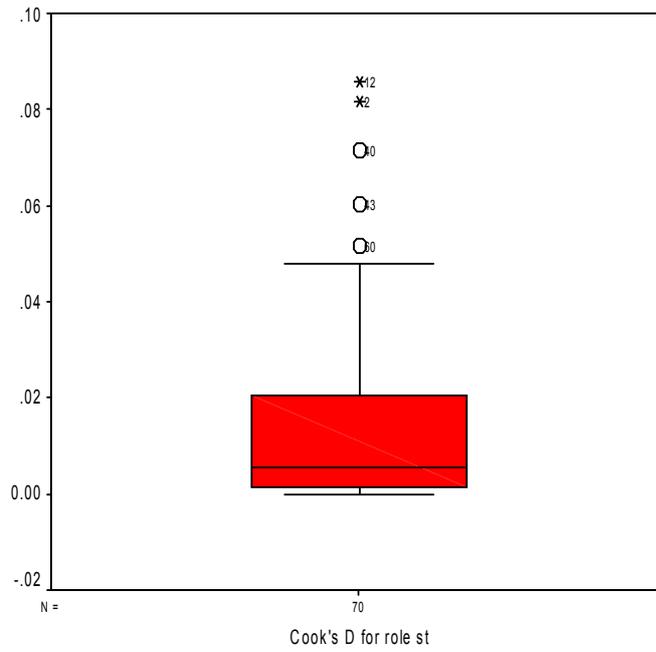


Figure 3: Box-plot of Cook's D for the IVs and DV of the Role Strain regression to determine outliers. Two participants' data (numbers 2 & 12) was excluded from the final hierarchical regression analysis.

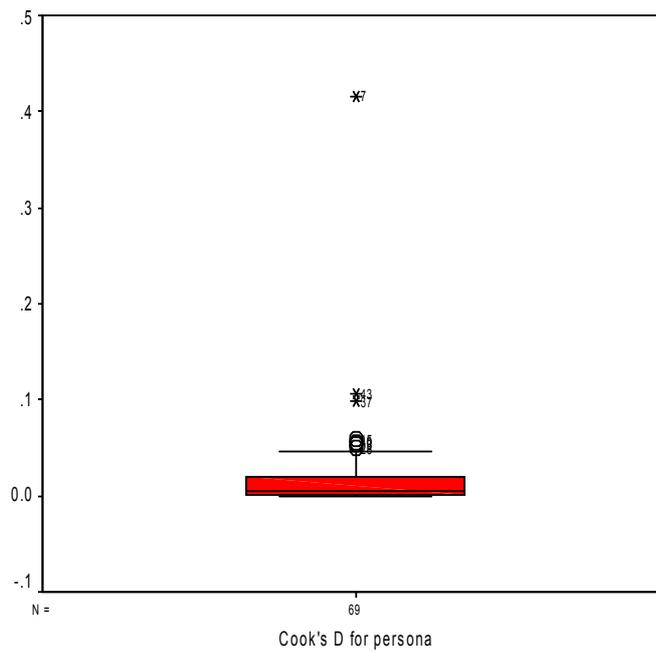


Figure 4: Box-plot of Cook's D for the IVs and DV of the Personal Strain regression to determine outliers. One participant's data (number 7) was excluded from the final hierarchical regression analysis.

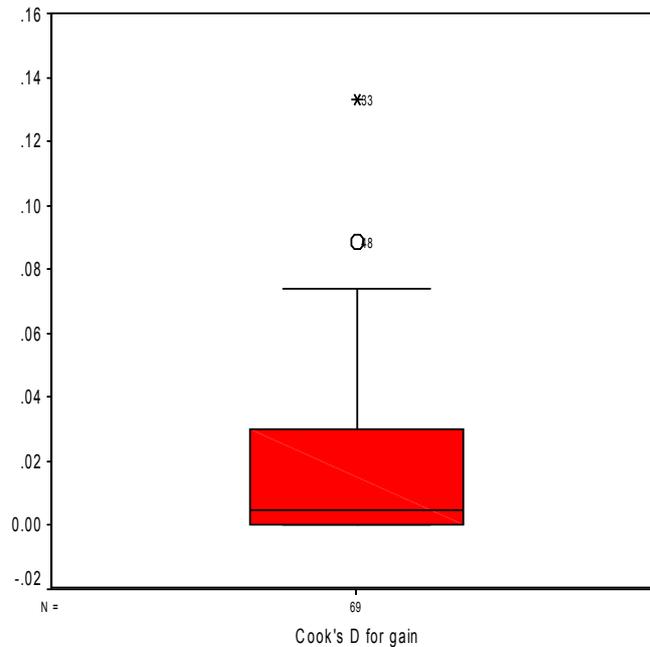


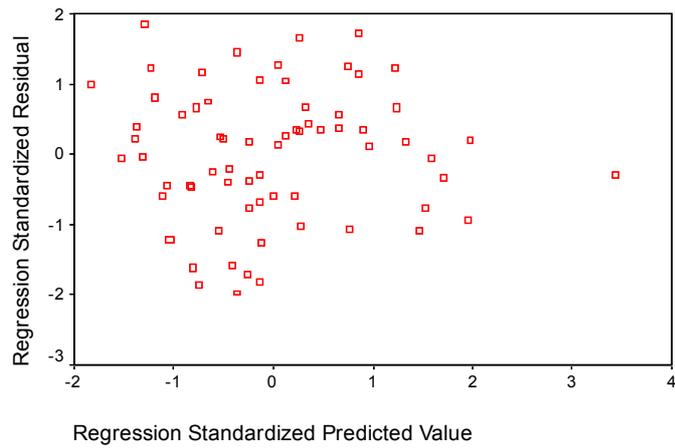
Figure 5: Box-plot of Cook's D for the IVs and DV of the Gain regression to determine outliers. One participant's data (number 33) was excluded from the final hierarchical regression analysis.

The relevant participant corresponding to the extreme scores in each data set was then excluded from the each regression analysis. For the regression analysis on Role Strain, participant number 7 was excluded. For the regression analysis on Personal Strain, participants number 2 and 12 were excluded. For the regression analysis on Gain, participant number 33 was excluded.

The linearity and homoscedascity of the data sets were assessed using residual scatterplots. These are shown below and can be assumed to satisfy the assumption of linearity and homoscedascity by their uniform spread of scores (see Tabachnik & Fidell, 2001: p120).

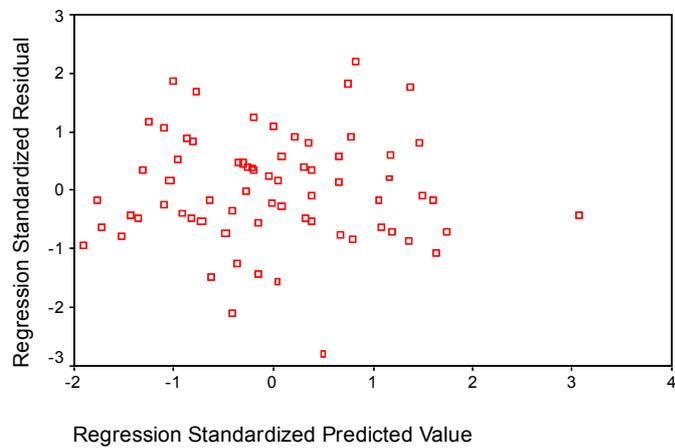
Scatterplot

Dependent Variable: ZBIROLE



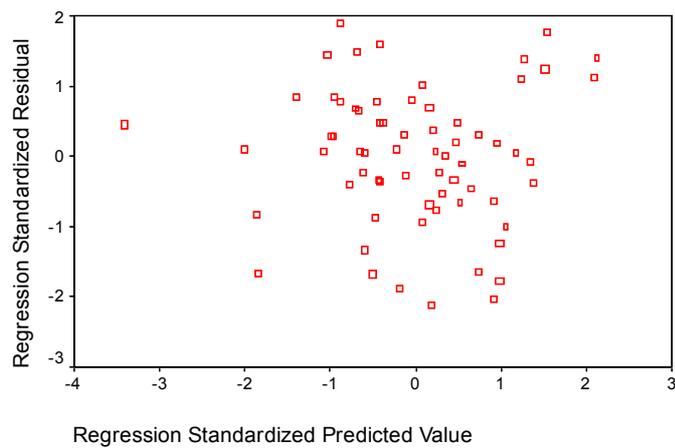
Scatterplot

Dependent Variable: ZBIPERS



Scatterplot

Dependent Variable: GAIN



Finally the collinearity of the independent variables used as predictors was assessed using the tolerance and variance inflation factors from the SPSS output. These are shown

below in table form for the final step in each regression analysis. None of the variables indicated any threat of multicollinearity.

Table 19: Colinearity statistics for the Role Strain independent variables.

Role Strain IVs	Tolerance	VIF
Health	.732	1.366
Number of Helpers	.768	1.302
Duration of caring	.930	1.075
Reaction to MBP	.677	1.476
PAQ m/instrumentality	.742	1.348
PAQ f/expressiveness	.707	1.415
GRCS - SPC	.827	1.210
GRCS - RABBM	.894	1.119

Table 20: Colinearity statistics for the Personal Strain independent variables.

Personal Strain IVs	Tolerance	VIF
Health	.757	1.322
Number of Helpers	.841	1.189
Duration of caring	.946	1.057
Reaction to MBP	.703	1.422
PAQ m/instrumentality	.758	1.319
PAQ f/expressiveness	.750	1.333
GRCS - SPC	.838	1.193
GRCS - RABBM	.911	1.098

Table 21: Colinearity statistics for the Gain independent variables.

Gain IVs	Tolerance	VIF
Education	.860	1.162
PAQ m/instrumentality	.826	1.210
PAQ f/expressiveness	.815	1.227
GRCS - SPC	.873	1.145
GRCS - RABBM	.873	1.145

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Appendix 10: ANOVA tables comparing median-split PAQ groups.

The PAQ has often been used to categorise respondents into four groups: 'androgynous' for participants rating high on both the instrumental and expressive scales; masculine for high instrumental and low expressive ratings; feminine for high expressive and low instrumental ratings; and undifferentiated for rating low on both scales.

Many studies using instrumental and expressive traits to investigate mental health have suggested that androgyny is linked to positive coping with stress (Shifren & Bauserman, 1996). People who rate themselves high on both the instrumental and expressive scales are said to have a more flexible self-identity and use more adaptive psychological responses (Markstrom-Adams, 1989; Shifren & Bauserman, 1996). In contrast, people rating themselves as more stereotypically masculine (high instrumental, low expressive) appear to present with low-levels of self-esteem, depression and anxiety as well as other measures of emotional distress (Whitley 1983). Androgynous individuals have also been shown to report fewer illness symptoms, similar to individuals scoring high on instrumental traits alone (Wech, 1983), but they express a greater willingness to seek help like individuals scoring high on expressive traits (Johnson, 1988).

In caregiving, men who self-report an androgynous profile of traits may respond better to the demands of caring for their wife because they may be more comfortable with expressive characteristics such as nurturance and empathy (Sachs, Chrisler, & Devlin, 1992). This may moderate the expression of instrumental characteristics such as being independent and feeling superior (Baffi et al., 1991), and they may be more likely to seek help (Johnson, 1988). In contrast, high levels of instrumentality together with low expressiveness may indicate a maladaptive response style and be related to higher levels of strain. It is unclear whether these will effect differential changes in appraisals of strain and Gain.

A fourth hypothesis for the current study is suggested from the above findings:
Men rating themselves as androgynous (high M/Instrumentality and high F/Expressive) will report less strain (personal and role) and more Gain than other men (instrumental, expressive, and undifferentiated).

To test this hypothesis, the participants were categorised, using a median split on their PAQ-F/Expressive and PAQ-M/Instrumentality scores, into 4 groups representing androgynous, high instrumental, high expressive, and undifferentiated. The mean and SD for each group is shown in the table below. Three ANOVA's were carried out to determine whether there were significant differences between the groups on the measures of Personal Strain, Role Strain and Gain measures. None of these indicated a significant difference for the four groups on any of the measures.

Table 22: Means (SDs) of the dependent variables for the participants grouped into androgynous, high masculine, high feminine and undifferentiated using median splits on their PAQ-F/Expressive and PAQ-M/Instrumentality scores.

Group	N	Role Strain	Personal Strain	Gain
Androgynous (high M, high F)	25	15.56 (6.4)	5.04 (2.7)	16.12 (4.5)
High masculine (low F)	10	14.00 (4.7)	4.70 (2.5)	15.80 (4.0)
High feminine (low M)	15	15.33 (6.5)	5.33 (2.7)	16.00 (3.7)
Undifferentiated (low M, low F)	20	18.30 (8.0)	6.55 (3.1)	13.90 (4.5)

These results do not support the hypothesis that androgynous men would report less strain and more Gain than the other groups of men measured in the PAQ F and M scales. Interestingly, the androgynous men reported higher Gain than the other men, but it was the high masculine/instrumental men who reported lower strain, although these differences are non-significant. The pattern of relationship between group and the dependent variables was more uniform for the undifferentiated group. These men reported the most strain and the least Gain, although again, not significantly so.

The analysis of variance tables for each of the dependent variables between the androgynous, high masculine, high feminine and undifferentiated groups measures on the PAQ.

Table 23: Analysis of variance of Role Strain between the four PAQ median-split groups.

	Sum of Squares	df	Mean Square	F	Sig.
Between groups	156.950	3	52.317	1.137	.340
Within groups	3035.693	66	45.995		
Total	3192.643	69			

Table 24: Analysis of variance of Personal Strain between the four PAQ median-split groups.

	Sum of Squares	df	Mean Square	F	Sig.
Between groups	34.142	3	11.381	1.498	.223
Within groups	501.343	66	7.596		
Total	535.486	69			

Table 25: Analysis of variance of Gain between the four PAQ median-split groups.

	Sum of Squares	df	Mean Square	F	Sig.
Between groups	64.946	3	21.649	1.205	.315
Within groups	1186.040	66	17.970		
Total	1250.986	69			

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Appendix 11: The Gender Role Conflict Scale

Description of the Gender Role Conflict Scale

The Gender Role Conflict Scale (GRCS) was developed from O'Neil and colleagues work with university and college students' attitudes about masculinity (O'Neil et al., 1986; O'Neil, 1995). The scale was designed to assess men's personal gender role attitudes, behaviours and conflicts. The 37 items are used with a six-point Likert-scale response to assess the degree of gender role conflict on four factors. The items and four factors were derived from a factor analysis of 85 items on six patterns of gender role conflict identified by O'Neil and colleagues in their clinical and research activities. The four factors are labeled Success, Power, and Competition, (SPC: 13 items); Restrictive Emotionality (RE, 10 items); Restrictive Affectionate Behaviour Between Men (RABBM, 8 items), and Conflict Between Work and Family Relations (CBWFR, 6 items). The items are intended to reflect direct or indirect consequences of traditional masculine gender roles, either directly or due to trying to deviate away from them.

O'Neil (1995) defines the constructs in the following way:

1. *Success*: Persistent worries about personal achievement, competence, failure, status, upward mobility and wealth, and career success.
Power: Obtaining authority, dominance, influence or ascendancy over others.
Competition: Striving against others to gain something or the comparison of self with others to establish one's superiority in a given situation.
2. *Restrictive Emotionality*: Having difficulty and fears about expressing one's feelings and difficulty finding words to express basic emotions.

3. *Restrictive Affectionate Behaviour Between Men*: Having limited ways to express one's feelings and thoughts with other men and difficulty touching other men.
4. *Conflicts Between Work and Family Relations*: Experiencing difficulties balancing work-school and family relations, resulting in health problems, overwork, stress, and a lack of leisure and relaxation.

Betz and Fitzgerald's (1993) critique of the factor structure of the GRCS has been useful in clarifying the item and content of the scale. They described the items as addressing the following:

1. Men use masculine stereotypes and norms to avoid appearing feminine.
2. Men worry about not achieving some masculine stereotypes or norms.
3. Men fear or experience devaluation, or restriction as a consequence of masculine stereotypes and norms, either from themselves or others.

GRC and older men

There are few studies that have investigated Gender Role Conflict in men over the age of 50. The vast bulk of research using GRCS is focused on young college and university aged men, reflecting the cohort on which the scale was developed.

At least one validity study has suggested that the GRCS has validity for older men as well as college-age men (Chamberlin, 1994). More recently, Hill and Donatelle (2005) explored the relationship between Gender Role Conflict and perceived social support in a sample of older men aged 40-86. They found that restrictive emotionality was a strong predictor of problems with social support in this cohort of men. Their findings led them to

question the idea that as men age they being to be less restrictive in their masculinity.

Theodore & Lloyd (2000) investigated the relationship between Gender Role Conflict and psychological well being in young, middle aged and older aged men in Australia. They found salient and understandable differences in SPC and CBWF between the three groups of men, but no significant differences between the groups on measures of RE and RABBM. They concluded that this runs counter to the commonly accepted view of men becoming more 'feminised' as they get older. They were tempted to conclude that warding-off emotions (RE) and avoiding male intimacy (RABBM) are stable male traits throughout a man's life. Thus, in terms of assessing the ways in which traditional masculinities interact with affect, the GRCS can be said to be a valid tool.

Conclusion

The validity of using the GRCS with older men is questionable with the wording of some of the items being more relevant to men of working age. However, as the above studies show, some of the constructs are relevant to the older cohort. There are no studies available that address the validity of the GRCS to a British population.

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