

The Male Face of Caregiving: A Scoping Review of Men Caring for a Person With Dementia

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Abstract

The purpose of this scoping review was to examine the empirical evidence published since 2007 on men as family caregivers of persons with dementia. Searches were conducted on Academic Search Complete, Ageline, CINAHL, Embase, Medline, PsychINFO, Social Work Abstracts, and Web of Science using database-specific controlled (i.e., MeSH terms) vocabulary related to dementia, men, and caregiving. Studies published in English between 2007 and 2012 that provided evidence of the experiences of male family caregivers of persons with dementia were included in the review. A total of 30 articles were selected for inclusion. Studies were grouped into three major themes for review: men's experiences of caregiving, relational factors, and outcomes of caregiving. The reviewed studies build on and support previous findings related to stress, burden, accessing services, and the importance of relational factors to men's caregiving experiences. However, there is a need for a framework that explains these findings in relation to masculinities. Such a framework would provide the necessary unifying context for a more powerful explanatory account. Furthermore, there appears to be the potential for great benefit in fully linking men's caregiver research to men's health issues as a means to articulate strategies to sustain the health and well-being of men caregivers. This seems especially relevant in light of the closing gender gap in life expectancy, which will ultimately see many men providing direct care to their partners.

Keywords

male caregivers, dementia care, healthy aging, gender, masculinities

Introduction

Dementia was recently named the health crisis of the 21st century with an estimated 35.6 million people worldwide living with dementia, a number that is expected to reach 115.4 million by 2050 (Wimo & Price, 2010). Most people with dementia require some form of care, ranging from assistance with daily living activities to full 24-hour care and supervision (Wimo & Price, 2010). Family caregivers of persons with dementia often experience higher levels of burden when compared with caregivers of persons with other chronic conditions (Campbell et al., 2008). Higher caregiver burden has been attributed to the severe and unpredictable nature of dementia, as well as the profound cognitive and behavioral deficits associated with the disease (Takano & Arai, 2005). The vast majority of family caregivers are female, but men are adopting caregiving roles at an increasing rate, making up almost 40% of caregivers in Canada (Baker, Robertson, & Connelly, 2010; Frederick & Fast, 1999) and 41% of

spousal caregivers in the United States (Brown, Chen, Mitchell, & Province, 2007). Rapid population aging coupled with a higher proportion of women affected by dementia compared with men means that the number of male family caregivers of persons with dementia is anticipated to increase. With this shift in caregiving trends, male family caregivers of persons with dementia are beginning to be represented in the caregiving literature (McDonnell & Ryan, 2013), and our understanding of the influence of gender-related factors on dementia caregiving is at a nascent stage (Baker et al., 2010).

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The literature on family caregiving in relation to multiple chronic health problems recognizes that the caregiving process is influenced by gender-related factors. For example, findings suggest that male caregivers have a more task-oriented approach to care whereas female caregivers use more emotion-oriented coping methods. Male caregivers may favor a more independent approach to caregiving, accessing less formal services and supports than their female counterparts (Baker & Robertson, 2008; Cahill, 2000; Zodikoff, 2007). These approaches inevitably affect both caregiver and care recipient. Male caregivers have been reported to struggle with the transition to the caregiving role due to the "feminine" nature of many caregiving tasks (Allen, 1994; Baker & Robertson, 2008) possibly explaining why male caregivers spend fewer hours performing personal care tasks than female caregivers (Brazil, Thabane, Foster, & Bédard, 2009; Navaie-Waliser, Spriggs, & Feldman, 2002) and why male caregivers often find tasks such as cooking and cleaning difficult (Allen, 1994). Female caregivers tend to report a higher degree of caregiver burden and psychological distress (Bookwala & Schulz, 2000; Dumont et al., 2006; Navaie-Waliser et al., 2002; Stajduhar et al., 2010); however, male caregivers may be reluctant to disclose feelings of burden or distress due to traditional views of masculinity that idealize self-reliance and stoicism (Baker et al., 2010; Bookwala & Schulz, 2000; Fromme et al., 2005).

Two recent literature reviews focused on the specific aspects of male caregiving of persons with dementia. Baker and Robertson (2008) conducted a systematic review focusing specifically on how men cope with caregiving for a person with dementia ($n = 93$). McDonnell and Ryan (2013) explored caregiver burden, men in the caregiver role, support services, and the experiences of sons as caregivers of relatives with dementia using a non-systematic approach. Building on the review completed by Baker and Robertson (2008), the purpose of this scoping review was to examine the empirical evidence published since 2007 on men as family caregivers of persons with dementia. A scoping review summarizes evidence to convey the "breadth and depth of a field" offering a map of current understandings and identifies gaps in the evidence. Furthermore, although a scoping review may not provide a structured quality assessment of the studies reviewed, it will provide some analytic reinterpretation of those studies (Levac, Colquhoun, & O'Brien, 2010). This scoping review used a systematic method to identify, review, and thematically analyze the past 5 years of evidence on men as family caregivers of persons with dementia. It differs from the review undertaken by McDonnell and Ryan (2013) in that a systematic method was used. A broader perspective of caregiving was also taken than that found in the Baker and Robertson (2008) review, which solely focused on coping.

This scoping review was conducted with a focus on sex and gender-related influences on caregiving. By definition sex refers to the biology of what makes up males and females, and how anatomical and physiological differences influence disease, health behaviors, and illness outcomes (Johnson & Repta, 2012). In contrast, gender refers to socially constructed performances that are influenced by norms and practices about what it is to be a woman or a man (Connell, 2005). While sex and gender are inextricably linked (i.e., physical strength and the types of work men are affirmed in doing), Connell's (2005) masculinities framework has prevailed and is premised on two key gender concepts. One, dominant ideals of masculinities include power relations whereby men most often exert control over others. Characteristics of stoicism, self-reliance, and competitiveness are understood as dominant ideals of masculinity. Two, while these power differentials and characteristics are idealized masculine performances, the degree to which men (and women) comply, embody, and engage them reveal great diversity.

The masculinities and men's health research has focused on men's health help-seeking (Galdas, Cheater, & Marshall, 2005) and a range of men's illness experiences including prostate cancer (Oliffe, 2005) and depression (Oliffe, Ogrodniczuk, Bottorff, Johnson, & Hoyak, 2012) have been described. Within this emergent literature, dominant ideals of masculinity have been highlighted as both risky and health promoting (Robertson, 2007; Sloane, Gough, & Conner, 2010). For example, while self-reliance might prohibit some men from seeking professional medical help, the same characteristic lends itself well to men's illness self-management. The masculinities framework has also been used to theorize men's actions and inactions in other contexts including paid work and heterosexual relationships (Hearn, 1992); however, this research rarely explicitly engages men's health as an intertwined issue. Given the focus on gender influences in relation to the experiences of men caring for family members with dementia, an area of inquiry for the review was evaluating adaptations of the masculinities frameworks. In summary, the purpose of this scoping review was to examine the empirical evidence published since 2007 on men as family caregivers of persons with dementia.

Method

Although the method of this review was systematic, it is best categorized as a scoping review because the purpose was to review and summarize the body of available evidence without assessing study quality (Daudt, van Mossel, & Scott, 2013; Davis, Drey & Gould, 2009; Levac et al., 2010). A search was conducted in February 2012 of the electronic databases Academic Search

Complete, Ageline, CINAHL, Embase, Medline, PsychINFO, Social Work Abstracts, and Web of Science using database-specific controlled (i.e., MeSH terms) vocabulary related to Alzheimer's disease, dementia, gender, caregiving, and familial relationships (e.g., husband or son). Each database was searched to identify controlled vocabulary. For example, CINAHL was searched for the terms "caregiver" and "carer," and it was determined that the controlled term "caregivers" could be used in the search string. Web of Science had no controlled vocabulary function so both the terms "caregiver" and "carer" were used in the search string. Limits were set to the years of 2007 onward and English language articles only (see Figure 1 for search results). After removing duplicates, records were loaded into EPPI-Reviewer 4, a software program for managing literature review data, and screened. Inclusion and exclusion criteria were established through an iterative process of joint review by the investigators. Empirical studies that provided disaggregated data on men's and women's caregiving experiences in the context of dementia were included. These articles needed to include data on gendered experiences. For example, articles that focused on specific caregiving tasks in relation to the sex of the caregiver, without a gendered analysis, were not included. Book chapters, conference proceedings, dissertations, and articles without an abstract or a title that did not explicitly refer to the topic in the title were excluded. Furthermore, studies that aggregated male caregiving in the context of dementia with other psychogeriatric disorders and studies where the person with dementia resided in an institution rather than home were excluded. A total of 30 articles were selected for inclusion in the literature review (Figure 1). Reference lists of the selected articles were reviewed to determine if key publications had been missed. No additional publications were found. To summarize the findings of the studies, a data abstraction table was created using the following categories: (a) citation, (b) study design, (c) sample size and composition, (d) theory framework (if related to gender), (e) primary objectives, (f) instruments, and (g) relevant findings. The articles were then thematically grouped based on their primary focus and key findings (Table 1).

Results

Studies included in this review were conducted in the United States, Canada, the United Kingdom, Portugal, Spain, Turkey, Switzerland, Brazil, Sweden, Korea, Norway, Finland, South Africa, and Cyprus. The studies were descriptive in design and used qualitative ($n = 14$), quantitative ($n = 14$), and mixed ($n = 2$) methods of inquiry. The majority of the studies compared male and female family caregivers of persons with dementia ($n =$

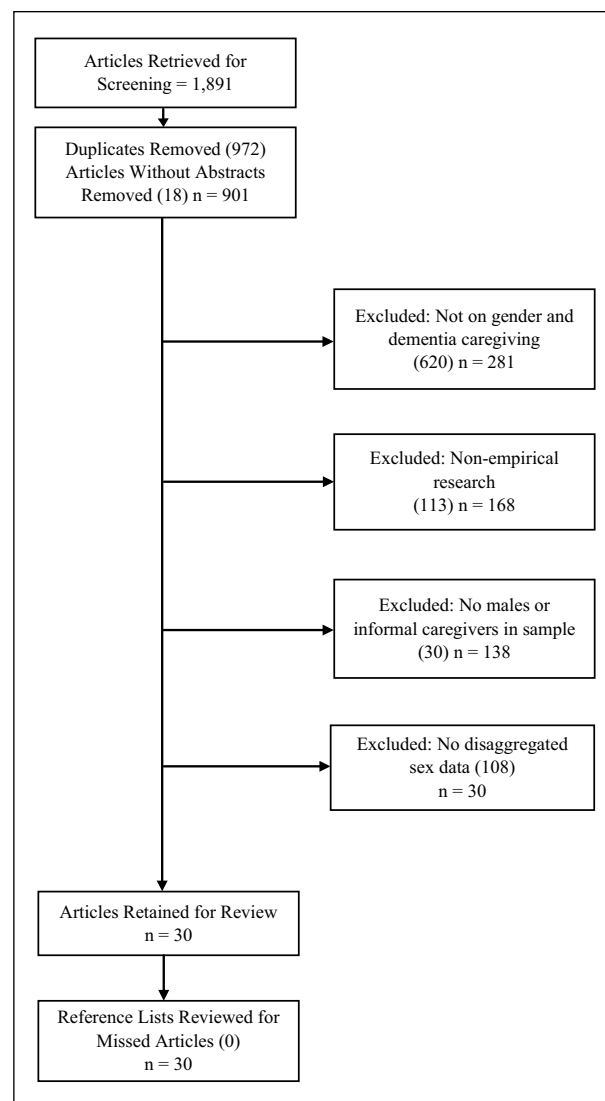


Figure 1. Literature screening procedure.

17) and focused on spousal caregiving ($n = 21$). Thirteen studies focused solely on male family caregivers of a person with dementia. Three major themes were identified from the studies: men's experiences of caregiving ($n = 14$), relational factors in caregiving ($n = 6$), and stress-related outcomes of caregiving ($n = 10$; Table 1).

Men's Experiences of Caregiving

Fourteen of the reviewed studies focused on the experience of caregiving for a family member with dementia. With the exception of one study (Sun et al., 2008) all employed qualitative methods. The findings will be reported in relation to four subthemes: men's constructions of caregiving as men's work, the "man-made" challenges of caregiving, men's help-seeking experiences,

Table 1. Themes and Associated Studies.

Reference	Method/sample/gendered framework	Primary objectives	Instruments	Relevant findings
<i>Theme 1. Experiences of Caregiving</i>				
Atta-Konadu, Keller, and Daly (2011)	Qualitative (grounded theory); N = 9 male spousal caregivers	To explore the experiences of male caregivers and their wives as they adjust to food-related role changes	None	Husbands without gendered role expectations were able to transition into the food-related role with minimal reservations. Husbands with gendered role expectations were reluctant to take up food roles and found the experience to be tedious and extrinsic to their nature as men
Black, Schwartz, Caruso, and Hannum (2008)	Qualitative (phenomenological method of inquiry); N = 4 male spousal caregivers	To explore the experiences of suffering in elderly husband caregivers and how they mediate their suffering	None	Three strategies men used to mediate their suffering were identified: (a) the power of the "little" aspects of everyday incidents, (b) preserving both self and marriage identity, and (c) finding purpose in the caregiving role.
Brown et al. (2007)	Qualitative (grounded theory); N = 9 male spousal caregivers	To gain an understanding of the help-seeking process of older husbands caring for wives with dementia	Non	Attitudes, values, experiences, cost, availability, and myriad other conditions influenced help-seeking choices. Negative experiences with service providers also influenced future choices with accessing services.
Calasanti and King (2007)	Qualitative (in-depth interviews using a constructivist approach); N = 22 husband caregivers; Structural Feminist Framework	To examine husband's experiences of caring for their wives with Alzheimer's disease from a structural feminist perspective	None	The strategies and approaches to caregiving were rooted in the caregiver's sense of selves as males. Six approaches to coping with problems associated with caregiving were identified: use of force, concentrating on tasks, controlling one's emotions, self-medication, maintaining normalcy, and diverting attention to other activities.
Fjellström, Starkenberg, Wesslen, Bäckström, and Faxén-Irving (2010)	Qualitative (exploratory focus groups); N = 17 spousal caregivers (11 female, 6 male)	To examine how people living with persons with Alzheimer's disease perceive food-related work such as cooking and food choices	Mini Mental Status Exam (MMSE)	The males in this study had concerns about being a good food provider for their spouses. Many were concerned about managing food and meeting their partner's nutritional needs. They generally lacked knowledge and experience in shopping, cooking, and food prep.
Knutsen and Råholm (2009)	Qualitative (phenomenological method of inquiry); N = 9 male spousal caregivers	To understand how male caregivers experience and manage the strain of caregiving and gain insight into the experience of men who care for their wives with dementia	None	The male caregivers in this study suffered from grief, loneliness, and isolation. They dealt with feelings of alienation and abandonment while also experiencing reconciliation from feelings of love and devotion toward their spouses

(continued)

Table 1. (continued)

Reference	Method/sample/gendered framework	Primary objectives	Instruments	Relevant findings
Neufeld and Kushner (2009)	Qualitative (ethnography study); N = 34 male caregivers (24 spouses, 10 sons)	To identify primary caregivers' perceptions of nonsupportive and supportive interactions in relationships with kin and friends as well as professionals	None	Men caregivers identified a lack of orientation to the caregiving situation, an unsatisfactory linkage to support sources, insufficient support, and hurtful interactions as nonsupportive interactions.
Pretorius, Walker, and Heyns (2009)	Mixed methods; N = 10 male spousal caregivers	To explore the experiences of men caring for spouses suffering from dementia	General Health Questionnaire (GHQ); Caregiver Burden Inventory (CBI); Satisfaction with Life Scale (SWLS); Sense of Coherence Scale (SOC); Fortitude Questionnaire (FORQ)	Males were found to have a task-oriented and problem-solving approach to caregiving. Effective male caregivers in this study were characterized by their ability to effectively use support services and find meaning in the caring role. Despite facing some challenges, men appear to be capable of successfully engaging in the caregiver role.
Ribeiro, Paul, and Nogueira (2007)	Qualitative (in-depth interviews); N = 53 male spousal caregivers (27 spousal caregivers had wives with dementia); Social constructivist perspective to understanding masculinities	To explore the experiences of older husbands caring for their dependent wives, their attitudes about their caregiving role, and their self-perception as men within the caregiving role	None	Participants negotiated with the traditional masculine ideology to preserve their masculinity and legitimize their presence in a predominantly feminine role. Gender-based social networks highly influenced the men's masculine identities.
Ribeiro and Paul (2008)	Qualitative (in-depth interviews); N = 53 male spousal caregivers (27 spousal caregivers had wives with dementia)	To examine the positive and rewarding aspects of caregiving and explore the differences between the positive references made by the men who were caring for a wife who had dementia and those made by men whose wives had physical impairments	None	The husbands who cared for wives with dementia were found to be more likely to report positive experiences associated with caregiving. They often found satisfaction in protecting their wives' well-being and assuring that they received good care. This was a common reason why the caregivers did not want to move their wives to institutions.

(continued)

Table 1. (continued)

Reference	Method/sample/gendered framework	Primary objectives	Instruments	Relevant findings
Russell (2007)	Qualitative (in-depth interviews from a social constructivist perspective); N = 30 male spousal caregivers; Social constructivist perspective to understanding masculinities	To examine the work of elderly men caregivers who care for wives with cognitive impairment related to Alzheimer's type dementia, stroke, brain injury, or other causes	None	Many men struggle with taking on the caregiving role due to gender norms and traditional views of masculinity. However, men are engaging in personal and hands on care more than they did in the past.
Sanders (2007)	Qualitative (phenomenological method of inquiry); N = 20 male spousal caregivers of PWD (18 husbands, 2 sons)	To examine the experiences of rural male caregivers of older adults with their informal support networks	None	While some of the caregivers have good relationships with informal supports and believe asking for assistance is acceptable, others were reluctant about asking for help and reported feelings of isolation.
Sanders and Power (2009)	Qualitative (phenomenological method of inquiry); N = 17 male spousal caregivers	To examine the changes that occur in the roles, responsibilities, and relationships of husbands who provide care for their wives with memory loss and other chronic health conditions	None	The husbands in this study had to negotiate between their marital roles and their roles as caregivers. This often involved finding ways to adapt to their new relationships with their wives.
Sun, Roff, Klemmack, and Burgio (2008)	Quantitative (surveys administered during in-home interviews); N = 720 family caregivers (165 males, 555 females)	To explore how male and female family caregivers differ in their use of formal services and informal support and how religiousness may affect such differences	MMSE	The males in this study reported using more in-home services than females, but less informal supports than females.

(continued)

Table 1. (continued)

Reference	Method/sample/gendered framework	Primary objectives	Instruments	Relevant findings
<i>Theme 2. Relational Factors in Caregiving</i>				
Davies, Sridhar, Newkirk, Beaudreau, and O'Hara (2012)	Quantitative (cross-sectional design); N = 162 persons with dementia and their spousal caregivers	To evaluate the impact of gender differences on intimacy and sexual satisfaction in marital relationships when one partner has Alzheimer's disease	Neuropsychiatric Inventory (NPI); MMSE; Caregiver Experience Questionnaire (CEQ); California Dementia Behavior Questionnaire (CDBQ); Experience of Intimacy with Partner Scales (EOIPS); Blessed Roth Dementia Rating Scale (BRDRS); Geriatric Depression Scale (GDS)	Female caregivers reported more symptoms of emotional distress, which was linked to their satisfaction with intimacy when compared to male caregivers.
Dourado, Finamore, Barroso, Santos, and Laks (2010)	Mixed methods (semistructured interviews, assessments, and questionnaires were administered to participants); N = 36 persons with dementia and their spousal caregivers (14 male caregivers, 22 female)	To investigate the presence of sexual activity and satisfaction between patients and their spouses	Questionnaire on Sexual Experience and Satisfaction; Cornell Scale for Depression in Dementia; Clinical Dementia Rating (CDR); Assessment Scale of Psychological Impact of Dementia (ASPID); Zarit Burden Interview (ZBI); MMSE	Men associated sexual dissatisfaction with sadness, and women reported feelings of a lack of intimacy and an increase of anxiety.
Hayes, Boylstein, and Zimmerman (2009)	Qualitative (in-depth interviews using social constructionist, symbolic interactionist approach); N = 28 spousal caregivers (13 male, 15 female)	To examine how caregivers of spouses diagnosed with Alzheimer's disease perceive identity changes in themselves and their spouses, and how these changes affect marital intimacy and reciprocity	None	Husband caregivers were more interested in sexual intimacy than caregiving wives and therefore maintained sexually active longer and pursued sexual activity more frequently than wife caregivers. Behavioral changes, cognitive decline, and identity changes were less problematic for husband caregivers for maintaining sexual and physical intimacy.
Hayes, Zimmerman, and Boylstein (2010)	Qualitative (interpretive method); N = 28 spousal caregivers (13 male, 15 female); Gender Relations framework	To analyze the process of redefining marital relations within the context of couples dealing with Alzheimer's disease	None	Men were slower to recognize symptoms of Alzheimer's disease in their spouses and often normalized their wives condition. However, once symptoms were brought to their attention, they took action quickly.

(continued)

Table 1. (continued)

Reference	Method/sample/gendered framework	Primary objectives	Instruments	Relevant findings
Perren, Schmid, Herrmann, and Wettstein (2007)	Quantitative (secondary longitudinal analysis of an existing data set); N = 116 married couples (62% female caregiver; 38% male caregiver)	To investigate the impact of attachment style on the course of dementia-related problem behavior and caregivers' well-being	CDR; MMSE; NPI; Collins and Read Questionnaire; Schedule for the Evaluation of Individualized Quality of Life (SEIQoL)	Male spousal caregivers in this study exhibited more secure attachment patterns and reported higher levels of well-being than the female spousal caregivers. Despite this, male caregivers reported higher levels of anxiety and were more concerned about being abandoned by their wives than female caregivers.
Sanders and Power (2009)	See above	See above	See above	Many of the men commented that their relationships with their wives after their illness led to an enhanced sense of closeness, intimacy, and sexual connection.
Winter, Gitlin, and Dennis (2011)	Quantitative (used baseline data from individuals with dementia and their family caregivers who were enrolled in a randomized study); N = 237 persons with dementia and their spousal caregivers (202 females, 35 males)	To examine how quality of relationship affects a family caregivers' desire to institutionalize their relative	Mutual Communal Behavior Scale (MDBS); Cultural Justification for Caregiving Scale (CJCS); Agitated Behavior in Dementia Scale (ABDS); MMSE	It was found that male caregivers that reported poor premorbid relationships with the care recipient were more inclined to place their relatives in institutions.
<i>Theme 3. Outcomes of Caregiving</i>				
Akpınar, Küçüküçlü, and Yener (2011)	Quantitative (comparative descriptive study); N = 191 caregivers (120 female, 71 male)	To determine the effects of gender on caregiver burden	MMSE; Neuropsychiatric Inventory (NPI); Caregiver Burden Inventory (CBI)	Female caregivers reported higher level of caregiver burden than male caregivers. This may be because men may be reluctant to report the difficulties they face in their jobs and roles and may hide their true emotions.
Baker et al. (2010)	Quantitative (survey questionnaires); N = 70 male spousal caregivers	To explore how masculinity relates to male caregivers' appraisals of strain and gain in dementia care	Personal Attributes Questionnaire (PAQ); Gender Role Conflict Scale; Zarit Burden Interview (ZBI); Caregiver Satisfaction Scale (CSC)	Male caregivers with traditional views of masculinity are more likely to report that they are not experiencing burden or that they feel uncertain about being in the caregiver role. They are also more likely to express positive aspects of spousal caregiving when compared to men with less traditional views of masculinity.

(continued)

Table 1. (continued)

Reference	Method/sample/gendered framework	Primary objectives	Instruments	Relevant findings
Campbell et al. (2008)	Quantitative (cross-sectional design); N = 74 persons with dementia and their family caregivers (58% of family caregivers were female; 42% male)	To investigate the factors associated with caregiver burden.	MMSE; NPI; ZBI; Bristol Activity of Daily Living Scale (BALDS); Caregiver Stress Scale (CSS); List of Threatening Events Questionnaire (LTEQ); Eysenck Personality Questionnaire; Marital Satisfaction Questionnaire for Older Persons (adapted)	Females are at a higher risk of caregiver burden than male caregivers.
Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch, and López-Pousa (2010a)	Quantitative (cross-sectional analytic design); N = 112 spousal caregivers and 139 adult-child caregivers (70 men, 166 women)	To identify and compare the factors associated with caregiver burden among spouse and adult-child caregivers	Cambridge Cognitive Examination Revised (CAMCOG-R); Cambridge Mental Disorders of the Elderly Examination Revised (CAMDEX-R); Behavioral & Psychological Symptoms of Dementia (BPSD); Disability Assessment for Dementia (DAD); SF-36 Health Survey; CBI; MMSE	Sons showed the highest level of burden and poor mental health (followed by daughters, wives, and husbands).
Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch, and López-Pousa (2010b)	Quantitative (cross-sectional analytic design); N = 103 spousal caregivers and 109 adult-child caregivers (70 men, 166 women)	To identify the differential variables in perceived quality of life between patients and caregivers, distinguishing specifically between spouse and adult child caregivers	Quality of life in AD (QoL-AD); CAMDEX-R; BPSD; DAD; SF-36 Health Survey; CBI; MMSE	Sons reported the highest level of burden and exhibited the poorest mental health. Daughters showed the highest correlations between perceived quality of life of the care recipient and level of burden.

(continued)

Table 1. (continued)

Reference	Method/sample/gendered framework	Primary objectives	Instruments	Relevant findings
Hong and Kim (2008)	Quantitative (cross-sectional design); N = 157 family caregivers (41 daughters, 21 sons, 53 daughters in law, 42 spouses)	To investigate family caregiver burden by relationship to care recipient	MMSE (translated); ADL/IADL Scale; Memory and Behavior Check List (MBC); Personal Resource Questionnaire (PRQ-85); Burden Inventory written in Korean (KBI)	Sons experienced the lowest burden of care, whereas daughters experienced the highest.
Mills et al. (2009)	Quantitative (polysomnography and assessment of dementia severity and caregiver stress); N = 81 spousal caregivers (23 males, 58 females)	To examine the effects of caregiver gender and severity of the spouse's dementia on sleep, coagulation, and inflammation in the caregiver	CDR; NPI; Pearlin Role Overload Scale; Polysomnography (PSG)	Male caregivers who were caring for partners with severe dementia experience more disturbed sleep and greater coagulation than female caregivers supporting partners with severe dementia.
Norton et al. (2010)	Quantitative (population based study); N = 1,221 married couples	To examine the effects of caring for a spouse with dementia on the caregiver's risk for incident dementia	MMSE; Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)	Findings indicate that the male spouses in this study are at greater risk for dementia than female spouses. However, due to the overlap in confidence intervals, this finding could be due to chance.
Valimäki, Vehviläinen-Julkunen, Pietilä, and Pirttilä (2009)	Quantitative (cohort study); N = 170 persons with dementia and their spousal caregivers (107 female caregivers, 63 males)	To examine the sense of coherence (SOC) of spousal caregivers, and investigate the association of SOC, health-related quality of life, depressive symptoms, distress and how severity of Alzheimer's disease affects SOC	SOC; Health Related Quality of Life Scale (HRQoL); Beck Depression Inventory (BDI); GHQ; MMSE; CDR; NPI	The male caregiver's sense of coherence was significantly higher than the female caregivers in this study. The female caregivers reported more depressive symptoms and distress, but male caregivers' depressive symptoms were more strongly associated with the care recipient's neuropsychiatric symptoms.
Papastavrou, Tsangari, Kalokerinou, Papacostas, and Sourtzi (2009)	Quantitative (cross-sectional study); N = 172 family caregivers (40 male, 132 female) (83 daughters, 10 sons, 28 husbands, 43 wives, 8 other)	To explore family burden in the care of patients with dementia and to look at gender differences in caregiver burden, psychiatric morbidity and coping	ZBI; Memory and Behavior Problems Checklist (MBPC); Ways of Coping Questionnaire; Center of Epidemiological Studies Depression Scale (CES-D)	Female caregivers had higher levels of depression and psychological morbidity than males. However, males may experience similar levels of depression and psychological morbidity but are less likely to report their symptoms. Male caregivers used a practical approach to responding to caregiving challenges and try to create psychological distance between themselves and the care recipient.

Men's Experiences of Caregiving
➤ Men's constructions of caregiving as men's work
➤ The 'man-made' challenges of caregiving
➤ Men's help-seeking experiences
➤ Men's ways of managing suffering and finding happiness in caregiving
Relational Factors in Caregiving
➤ Perceptions of sexual satisfaction and intimacy
➤ Attachment styles and patterns
➤ Gendered responses to symptoms
Stress-related Outcomes of Caregiving
➤ Caregiver burden
➤ Caregiver depression
➤ Other stress-related outcomes

Figure 2. Themes and related subthemes.

and men's ways of managing suffering and finding happiness in caregiving (Figure 2).

Men's Constructions of Caregiving as Men's Work. In five studies, researchers specifically aimed to understand how men see themselves *as men* in the caregiving role. The findings reveal the ways that men negotiated and co-opted traditional masculine ideals to preserve their masculinity and legitimize their engagement in a predominantly feminine role. For example, older husbands caring for dependent wives ($n = 53$; 27 of whom cared for wives with cognitive impairments due to dementia) were reported to construct their role as important and significant in ways that affirmed their sense of masculinity and self-worth (Ribeiro et al., 2007). These men also aligned to traditional masculine identities whereby their caregiving work traded on provider and protector roles. They associated caregiving with traditional masculine traits (e.g., stating "it takes guts") and positioned themselves as in control of the caregiving situation by emphasizing their role as head of the household. These men derived a sense of worth from taking on the additional responsibilities, and this in turn reaffirmed their sense of masculinity.

Similarly, others identified that male caregivers' strategies for dealing with the work of caregiving were rooted in their sense of themselves as men (Calasanti & King, 2007; Pretorius et al., 2009; Russell, 2007). In these studies, men's approach to caregiving was described as task-oriented and entailed identifying and mastering tasks in a manner similar to that of their previous workplace roles and careers. Men attempted to regain control of their lives by organizing caregiving tasks into a manageable routine (Black et al., 2008). Behaviors and paid work skills used in their prior careers, such as preparedness, knowledge, and silence to defend decisions they made, were adapted to their caregiver roles. Some men blocked emotions to

minimize the disruption of care work, and a few men self-medicated to support their caregiving work (Calasanti & King, 2007; Pretorius et al., 2009). These strategies to deal with caregiving work aligned with men's self-concepts as being strong, in control, and capable and supported their constructions of effective caregiving. The use of problem-focused coping was associated with positive caregiving experiences for men (Ribeiro & Paúl, 2008).

The "Man-Made" Challenges of Caregiving. Caregiving held unique challenges for male caregivers and this was addressed in five studies. The challenges were primarily related to roles associated with domestic chores including laundry, food preparation, and providing personal care. The task of food preparation was identified specifically in three studies as particularly challenging for men when transitioning to the caregiver role (Atta-Konadu et al., 2011; Fjellström et al., 2010; Russell, 2007). While being a good provider is traditionally considered part of a man's identity, Fjellström et al. (2010) reported that the men's identity as a *food* provider was marked by ambivalence. These authors raised food security as a gendered issue whereby inexperienced male food providers experienced significant difficulties in the context of providing dementia care. This is supported by Russell (2007), who reported that even for those husbands who had previously engaged in the food preparation role to some degree (typically as a special occasion activity, acknowledged as "heroic") the reality of assuming responsibility for daily meal planning and preparation was difficult. It was noted that gender socialization often leaves male caregivers without the knowledge and skills necessary to accomplish tasks related to food management. However, Ribeiro and Paúl (2008) noted that mastering difficult household tasks such as cooking enhanced husbands' sense of self-worth as well as marital closeness and intimacy.

The provision of personal care was an unexpected challenge for men as their partner's health status declined and marked a critical transition in caregiving (Russell, 2007; Sanders & Power, 2009). Sanders and Power (2009) reported that men had not considered they would have to assist with personal care tasks such as toileting, dressing, or bathing. As care needs transitioned, male caregivers drew on gendered repertoires such as viewing themselves as the protector and provider in the relationship and displaying pride in their ability to take on the caregiving role. Likewise, Russell (2007) in a study of men doing "women's work" reported that male caregivers of wives with dementia ($n = 30$) recounted extraordinary efforts to adapt to the daunting job of providing personal care. However, these men surprised themselves with how quickly providing competent personal care for their wives became part of everyday reality and routine. Indeed, like the men in the Ribeiro et al.'s (2007) study, intimately caring for their wives became a meaningful act

of husbandly devotion and a core element of their identity as a man. These actions might also be understood as embodying masculine virtues of selflessness and the direct protection of a significant other.

Men's Help-Seeking Experiences. Four studies focused on experiences of male caregiver help-seeking in the context of dementia. Three of the studies that focused solely on male caregivers concluded that negative experiences with formal as well as informal supports were a potent influence on future help-seeking behaviors (Brown et al., 2007; Neufeld & Kushner, 2009; Sanders, 2007). For example, Neufeld and Kushner (2009) investigated Canadian male caregivers' ($n = 24$) experiences and reported that participants' perceptions of nonsupportive interactions resulted from unmet expectations including a lack of orientation to caregiving, insufficient information necessary to navigate dementia caregiving, inadequate links to support resources and ineffectual communication, and/or hurtful interactions with support services. In sum, participants reported that formal services were difficult, intimidating, and bureaucratic throughout the caregiving process.

Husbands' choices regarding help-seeking strategies reported by Brown et al. (2007) were influenced by relational conditions such as family closeness; situational conditions such as cost, availability, and knowledge; and experiential conditions such as past experiences. These husbands used both formal and informal supports extensively and, like the men in Neufeld and Kushner's (2009) study, deeply appreciated when others took the initiative to offer support.

Sanders (2007) described patterns of informal support networks of rural male caregivers in the United States. While some men readily asked for help, others felt guilty asking for assistance, and others did not ask. It is important to note that when men did ask for help, they did not necessarily receive assistance. Furthermore, similar to the men in Brown et al.'s (2007), many men became isolated when their social networks diminished over time. It has been suggested that reports of men being less likely to use informal resources than female caregivers may relate to the fact that the men had significantly smaller social networks than did the women and so had more limited access to supports (Sun et al., 2008). All of the reported studies identified the importance of available informal social supports to male caregivers.

Men's Ways of Managing Suffering and Finding Happiness in Caregiving. Five studies addressed emotional aspects of men's experiences caring for wives with dementia. Men reported that dementia constrained their lives much as it did their wives (Black et al., 2008). Two studies reported that, by focusing on the little things, men achieved a

sense of control in a situation that was increasingly out of their control (Black et al., 2008; Knutsen & Råholm, 2009). This strategy supported both finding joy in a "smaller" life and managing sorrow by focusing attention on the immediate present rather than the future. Having some time of one's own on a daily basis was a strong recommendation from the men in Sanders and Power's (2009) study. Personal respite was viewed as critical to survival in the caregiving role.

Suffering was associated with ambiguous loss (she's here and she's not here), loneliness, missed communication with, caring by, and companionship from their wife, as well as guilt and shame when there was loss of patience (Black et al., 2008; Knutsen & Råholm, 2009; Pretorius et al., 2009; Sanders & Power, 2009). Men did not share their loneliness with their children (Black et al., 2008) but did want to talk with other men in the same situation (Knutsen & Råholm, 2009). The men identified themselves as husbands rather than as caregivers (Black et al., 2008; Knutsen & Råholm, 2009), and suffering was mediated by constructing the husbandly work of providing care as deeply meaningful. Men who experienced positive aspects of caregiving were proud of the work they did, felt pleasure in mastering difficult challenges, and experienced self-affirmation in being faithful to their marital relationship, which was highly valued (Black et al., 2008; Knutsen & Råholm, 2009; Pretorius et al., 2009; Ribeiro & Paúl, 2008; Sanders & Power, 2009). They appreciated social recognition, such as positive words from neighbors, health care providers, and sometimes their wives, who noted they were a special kind of husband (Black et al., 2008; Knutsen & Råholm, 2009; Ribeiro & Paúl, 2008). Caring was seen as a way to give back to their wives and provided an opportunity to develop something new and valuable in themselves, such as acceptance, compassion, empathy, and patience (Black et al., 2008; Knutsen & Råholm, 2009; Pretorius et al., 2009; Ribeiro & Paúl, 2008; Sanders & Power, 2009). For some husbands, providing care gave life purpose (Black et al., 2008; Pretorius et al., 2009) and was an enactment of love (Ribeiro & Paúl, 2008). In contrast, the men in Ribeiro and Paúl's (2008) study who did not report positive aspects of caregiving were motivated by a sense of obligation and caring was constructed more as a job than an intrinsic component of the marital relationship.

Relational Factors in Caregiving

Seven studies were reviewed that examined gender relations and differences in caregiving. However, the studies in this section tended to focus on sex differences in caregiving and report differing patterns among men and women caregivers, while masculinities and gender

relations receive little attention. These studies addressed three subthemes associated with relationship changes when a spouse has dementia: perceptions of sexual satisfaction and intimacy, attachment styles and patterns, and gendered responses to symptoms.

Perceptions of Sexual Satisfaction and Intimacy. Three studies addressed sexual satisfaction and intimacy comparing female and male spousal caregivers of persons with dementia (Davies et al., 2012; Dourado et al., 2010; Hayes et al., 2009). One study (Sanders & Powers, 2009) explored role transformations for men caring for wives with dementia and included findings related to intimacy. Male spousal caregivers were reported to be more interested in sexual intimacy than caregiving wives (Hayes et al., 2009). Consequently, they pursued sexual activity more frequently and maintained sexual activity longer than caregiver wives who had partners with dementia. When compared with female caregivers, issues related to behavioral changes and cognitive decline in the care recipient were less problematic for husband caregivers in relation to maintaining their spouses' essential identity as a wife rather than a dependent. This supported continuing sexual intimacy. In terms of masculinities and gender relations, these findings suggest that male caregivers predominantly connected intimacy to erection, penetration, and climax models of male sexuality and the dominant expression thereof.

Caregiver burden was associated with sexual dissatisfaction in caregivers of persons with dementia, but more so for women, who experienced higher levels of burden and lower levels of sexual satisfaction (Dourado et al., 2010). The men in Dourado et al.'s (2010) study, however, associated sexual dissatisfaction with sadness, which was not reported by female caregivers. Similar findings were reported by Davies et al. (2012) in their study on gender, sexual behaviors, and spousal caregiver well-being when one partner has dementia. These findings affirm male caregivers' alignment with dominant ideals of masculinity that value sexual intimacy and, therefore, grieve its loss. This is supported by others who identified that while some men were able to transform their intimate relationships with their wives to encompass new emotional closeness without physical intimacy, others experienced only loss (Sanders & Powers, 2009).

Attachment Styles and Relationship Patterns. Two studies addressed male caregivers' attachment styles and relationship patterns. Perren et al. (2007) investigated the influence of attachment style on dementia-related problem behaviors and on caregiver well-being among 116 spousal patient-caregiver dyads. Male spousal caregivers in this study exhibited more secure attachment patterns and reported higher levels of well-being compared with

female spousal caregivers. Despite this, male caregivers reported higher levels of anxiety and seemed more concerned about being abandoned by their wives than female caregivers. The authors attribute this to the possibility that older males have a smaller social network and therefore experience heightened anxiety over the anticipated loss of their wife. Winter et al. (2011) examined the impact of the quality of the premorbid relationship on family caregivers' ($n = 237$) desire to institutionalize relatives with dementia. The majority of male caregivers were husbands rather than sons or other relatives. Winter and colleagues reported that the quality of the relationship prior to the onset of dementia was significantly associated with a desire to institutionalize the care recipient for male caregivers, but not females. It is important to note that this finding applies to both the spousal and non-spousal caregivers.

Gendered Responses to Symptoms. Finally, one qualitative study examined gendered responses to symptoms of dementia in intimate relationships (Hayes et al., 2010). Results revealed that husbands were slower than wives to recognize symptoms of dementia shown by their partners. Many of the husbands in this study recognized cognitive changes in their partners, but normalized the spouse's behavior and did not associate these changes with dementia or the need for medical attention. Thus, husbands noticed their wives were having significant problems later in the disease process, but once this was recognized, they sought assistance more quickly than caregiver wives. The men in this study were also more willing to disclose the diagnosis of dementia to their ill spouse when compared with the caregiver wives.

Stress-Related Outcomes of Caregiving

Ten of the reviewed articles specifically focused on stress-related outcomes of caregiving for a family member with dementia. All of the studies were quantitative, with the majority being cross-sectional in design and offering only a comparison of male and female caregivers' level of burden. Male caregivers were underrepresented in all studies, with a majority of the participants being female. Only one study solely investigated how men experience the strains associated with caregiving for a family member with dementia (Baker et al., 2010). Three subthemes of stress-related caregiving outcomes were addressed within these studies: caregiver burden, caregiver depression, and other stress-related outcomes.

Caregiver Burden. Seven studies examined caregiver burden among family caregivers of a person with dementia (Akpınar et al., 2011; Baker et al., 2010; Campbell et al., 2008; Conde-Sala et al., 2010a, 2010b; Hong & Kim,

2008; Papastavrou et al., 2009). The research showed some consistency in how burden was defined, with five of the seven studies operationalizing their definition of burden by using either the long or brief version of the Zarit Burden Interview. Overall, the findings indicate that women experience higher levels of caregiver burden than men (Akpınar et al., 2001; Campbell et al., 2008; Hong & Kim, 2008; Papastavrou et al., 2009). However, it is interesting to note that among Turkish family caregivers, there was no gender difference with regard to emotional burden (Akpınar et al., 2011). Baker et al. (2010) identified that holding traditional masculine values was linked to positive appraisal about being an older male caregiver, which suggests the possibility that some men may under-report burden.

The findings with regard to gender and caregiving become varied and complex when kinship relations are taken into account. For example, Papastavrou et al. (2009) examined gender differences in caregiver burden and reported that, while female caregivers overall reported higher levels of burden than males, when kinship was taken into account there were no significant differences; husbands and wives reported similar levels of burden. Furthermore, husbands experienced significantly more burden than sons when providing care. This contrasts with the finding of Campbell et al. (2008), where kinship had no significant influence on burden, and with the findings of Conde-Sala et al. (2010b), where both wives and sons experienced more burden than husbands. Indeed, these researchers reported that "husbands, wives, daughters and sons, in this order, showed increasing levels of burden and progressively worse mental health" (p. 1269). Burden for husbands was strongly negatively correlated with perceived quality of life of the care recipient (Conde-Sala et al., 2010a). Finally, Hong and Kim (2008) studied family caregivers, most were daughters-in-law, and determined that spouses perceived more burden than other caregivers. Despite the complex relationships between burden, gender, and kinship, overall, the findings suggest that wives report more burden than husbands when caring for a person with dementia.

Caregiver Depression. Three studies examined the outcome of depression in relation to dementia caregiving (Conde-Sala et al., 2010b; Papastavrou et al., 2009; V€alim€aki, Vehvil€ainen-Julkunen, Pietil€a, & Pirttil€a, 2009). Papastavrou et al. (2009) reported that male caregivers experienced lower levels of depression when compared with women regardless of kinship (i.e., whether the men were husbands or sons). Similarly, Conde-Sala et al. (2010b) identified that husbands reported low levels of depressive symptoms and no significant relationships were found between burden and mental health. Anxiety and depression are reported to be significant problems for

both sons and daughters. Daughters who lived with the care recipient reported the highest burden and poorest mental health. V€alim€aki et al. (2009) conducted a study of spousal caregiver depression in relation to sense of coherence and health-related quality of life. Men caregivers reported fewer depressive symptoms, less distress, and higher sense of coherence than female caregivers. When men did report depressive symptoms, these were strongly associated with the care recipients' neuropsychiatric symptoms. This study suggests that a strong sense of coherence (the ability to comprehend a situation and cope) may be protective for men.

Other Stress-Related Outcomes. Two studies identified stress-related health sequelae associated with dementia caregiving (Mills et al., 2009; Norton et al., 2010). Norton et al. (2010) reported a six times greater risk of dementia for the caregiving spouse of a person with dementia, and when compared with caregiving wives, husbands were at higher risk. Mills et al. (2009) examined the effects of gender and dementia severity on spousal caregivers' stress, sleep, and inflammatory biomarkers related to cardiovascular disease. Male caregivers reported lower levels of overload stress than females. However, men caring for wives with worse dementia experienced significantly greater sleep disruption and higher circulating levels of coagulation biomarkers than women caring for husbands with worse dementia. The findings of both these studies suggest that stress is a significant issue for husband caregivers despite the findings of lower reported burden for men than women.

Limitations

The review did not account for study quality. The reconstruction of findings presented in the review did not account for cultural influences on masculinities, particularly in relation to men's experiences of providing care for a family member with dementia.

Discussion and Conclusion

The findings of this review demonstrate that there is a small but growing body of research focusing on male family caregivers of persons with dementia. The reviewed studies build on and support previous findings related to stress, burden, accessing services, and the importance of relational factors to men's caregiving experiences. The use of descriptive designs focused specifically on examining men's experiences as caregivers has provided an important foundation for future research. Unlike studies prior to 2007 reviewed by Baker and Robertson (2008), the results of this review point directly to the importance of gender-related influences in caregiving experiences for

men. However, while empirical insights to men's experiences of caregiving have distilled important understandings, gender and sex have emerged as somewhat interchangeable terms to explain prevailing patterns as well as diversity among men and differences between males and females.

Within approaches to gender analyses, the masculinities framework has emerged in the men's gender and caregiver literature. But despite demonstrated interest in gender differences, none of the reviewed dementia-specific studies employed gender frameworks or masculinities to inform their study design or analysis (e.g., Connell, 1987, 2005; Howson, 2006). As a result, the reviewed literature lacks nuanced depictions of male caregiving that acknowledge the diversity and differences within and across men's lives. Focusing on masculine ideals and how men do and do not reconcile the changes and challenges that come with providing direct care for their wives who have dementia affords important but truncated insights to what is a complex gender relations and health issue. Gender comparisons can inadvertently reify dominant ideals of masculinity and femininity in ways that ignore the diversity and efforts of many who take up or purposely employ "other" actions. The work of Galdas, Johnson, Percy, and Ratner (2010) reminds us that gender similarities are important to apprehend—especially as the field seeks to transition descriptive work toward interventions. In summary, the absence of potentially unifying and enriching theoretical frameworks continues to be a significant gap in the research literature.

Hanlon (2009a, 2009b) offers one example of a framework with strong potential for informing future research in the area. Hanlon argues that masculinities are critical to understanding relations between male caregivers and their care recipients. He posits there are three categories of men/masculinities at work in caregiving: *conventional masculinities*, *sharing masculinities*, and *caring masculinities*. *Conventional* men define their masculinity most strongly through traditional roles and responsibilities as bread winners and stereotypical divisions of labor drawing on essentialist discourses. These men view nurturing as "women's work" and are reluctant to perform caregiving tasks despite a strong sense of duty toward their family. *Sharers*, conversely, appear to be less rigid in their constructions of the gender division of labor and are often involved in all aspects of caregiving despite needing to work for pay for a good sense of self. However, they are acutely aware of the burdens associated with caregiving and would not willingly choose to care in place of paid work. *Caring or "care-full"* men have the strongest sense of caring responsibility and do not define their masculinity predominantly through paid work. They are willing to triage caring demands ahead of paid work and are more likely to find caregiving a deeply rewarding experience

as reported by Ribeiro et al. (2007) and Russell (2007). Hanlon argues that by "doing care" men can transform or reconfigure their masculinity on a deeper level. Applying a gender relations lens to caregiving research in the future may help explain the apparent variability in caregiving experiences and outcomes observed among male caregivers. Moreover, gender relations frameworks (see Howson, 2006) provide important opportunities to distil how masculinities and femininities are co-constructed in explaining men's engagement with the "work" of dementia caregiving.

The findings suggest that male spousal caregivers may experience high levels of physical stress yet report low levels of caregiver burden. There are several possible explanations for this potential discrepancy including that men may underreport the level of burden they experience or that existing burden instruments may not accurately speak to men's experiences of burden (Olliffe & Han, 2014). Other researchers have suggested that the problem-focused coping strategies used by male caregivers may mediate burden (Pöysti et al., 2012) and it could be argued that these coping strategies align well with masculine identities. Additionally, if men are able to maintain satisfactory intimacy longer than women, this may be protective in relation to burden. Men who are able to reframe the traditionally feminine aspects of caregiving as husbandly acts of devotion consistent with hegemonic masculinities may reinforce their valued identities, which also might be protective despite the stress induced by caregiving duties. The protective aspect may relate to a high sense of coherence, which has been associated with less distress and fewer depressive symptoms for men (Välimäki et al., 2009). It is conceivable that men such as those in the Ribeiro and Paúl (2008) study, most of whom successfully mastered the challenges of caregiving in a way that bolstered their sense of self-worth, may be better able to relate to their wives as wives despite the losses associated with dementia. This is supported by the finding that men tend to overlook or dismiss signs and symptoms of dementia shown by their wives (Hayes et al., 2010). Furthermore, men who are able to maintain a positive intimate connection with their wives may perceive their wives' quality of life as higher, which again seems protective in relation to burden (Conde-Sala et al., 2010a). Again, explicit attention to gender relations might shed light on how femininities that are linked to fragility and the need for support drive men's masculine ideals for having the strength and resilience to sustain their caregiver efforts.

Literature on relational well-being indicates that intimacy is an important component of spousal relationships for couples as they age. However, the well-being of an intimate relationship can significantly decrease when one partner has dementia (Clare et al., 2012; Davies et al.,

2012; Mittelman, Zeiss, Davies, & Guy, 2003). Few studies to date have examined gender-related differences in caregivers' perceptions of intimacy and relational well-being when a partner or spouse has dementia. Due to the sensitive topics explored in these studies, participants are limited to those individuals who are willing to disclose intimate details about their relationships. Therefore, the samples often lack heterogeneity, limiting the generalizability of findings. It seems that the quality of the marital relationship prior to the diagnosis of dementia is an important influence on men's experience of caregiving. For example, Winter et al. (2011) reported that the quality of the relationship prior to the onset of dementia was significantly associated with desire to institutionalize the care recipient for male caregivers, but not females. This lends further support to the importance of using gender relation frames to fully evaluate the intimacy satisfaction among couples where the woman experiences dementia.

Male caregivers' reluctance to access help services is well documented in the literature. However, the findings of this review suggest that in the context of caregiving different patterns of help-seeking may emerge. For example, men who perceived they should manage on their own, at times requested formal assistance, but it was always to address concerns for their wives rather than their own needs (Black et al., 2008; Knutsen & Råholm, 2009). Yet others report evidence of extensive seeking and acceptance of assistance among male caregivers. One possible explanation for some men's reluctance to seek help may be due to the constraints of holding traditional masculine values, such as can be seen with Hanlon's conservative masculinities (Baker et al., 2010). Just as these traditional masculine values may inhibit men from reporting burden, they may also constrain help-seeking.

There appears to be the potential for great benefit in fully linking men's caregiver research to gender relations and men's health issues as a means to articulate strategies to sustain the health and well-being of men caregivers. This seems especially relevant in light of the closing gender gap in life expectancy, which will ultimately see many men providing direct care to their partners.

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