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Caring for a spouse with advanced cancer: similarities and differences for male and female caregivers

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Abstract

Most caregiving literature has focused on women, who have traditionally taken on caregiving roles. However, more research is needed to clarify the mixed evidence regarding the impact of gender on caregiver/patient psychological outcomes, especially in an advanced cancer context. In this paper, we examine gender differences in caregiver stress, burden, anxiety, depression, and coping styles, as well as how caregiver gender impacts patient outcomes in the context of advanced cancer. Eighty-eight patients with advanced cancer and their caregivers completed psychosocial surveys. All couples were heterosexual and most caregivers were women (71.6%). Female caregivers reported significantly higher levels of perceived stress, depression, anxiety, and social strain compared with male caregivers, and female patients of male caregivers were more likely to use social support as a coping style compared with male patients of female caregivers. These findings highlight the potential differences between male and female caregivers' needs and psychological health.

Keywords

Caregiving; Gender; Spouse; Advanced cancer; Marriage

Introduction

In addition to the direct impact on patients, a diagnosis of cancer has direct implications for caregivers, especially spouse caregivers because they are frequently involved in direct care and management of the patient (Stenberg, Ruland, & Miaskowski, 2010; Stetz, 1987).

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Conflict of interest Dana Ketcher, Ryan Trettevik, Susan T. Vadaparampil, Richard E. Heyman, Lee Ellington, Maija Reblin declare that they have no conflict of interest.

Human and animal rights All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee (Chesapeake IRB, Pro00015311) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all patients for being included in the study.

Cancer is the third most common reason for adult caregiving (National Alliance for Caregiving, 2015), and can have important implications for psychological and physical health. Although some caregivers have reported benefits from providing care (Hudson, 2004; Kang et al., 2013; Wong, Ussher, & Perz, 2009), the negative outcomes associated with caregiving are important, have been well documented, and include outcomes such as high stress, poor health, unmet needs, depressive symptoms, and caregiver burnout (Fitzell & Pakenham, 2010; Girgis, Lambert, Johnson, Waller, & Currow, 2013; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Li, Mak, & Loke, 2013; Matthews, Baker, & Spillers, 2004; Northouse, Williams, Given, & McCorkle, 2012; Perz, Ussher, Butow, & Wain, 2011).

Caregivers of advanced cancer patients are at greater risk for adverse outcomes when compared with caregivers of other kinds of patients, which is likely due to increased need for physical care of the patient and greater emotional concerns (Andershed, 2006; Cameron, Franche, Cheung, & Stewart, 2002; Palos et al., 2011; Rumpold et al., 2016). Additionally, witnessing the deterioration or suffering of one’s partner, and coping with impending loss, may cause additional distress or depression for spouse caregivers more than other types of caregivers (Carr, House, Wortman, Nesse, & Kessler, 2001; Grunfeld et al., 2004; Kim & Schulz, 2008; Prigerson et al., 2003; Rossi Ferrario, Cardillo, Vicario, Balzarini, & Zotti, 2004). As such, patients with advanced cancer may need more attention (both physical and emotional) from their family caregivers, which may create increased pressure on the caregiver. Given these unique experiences, it is important that the literature expands from its primary focus on early-stage cancer to capture the experience of patients with advanced cancer and their spouse caregivers.

In understanding the demands placed on spouse caregivers, most literature has focused on women. Women provide most of the paid and unpaid acts of caregiving (National Alliance for Caregiving, 2015), and feelings and actions associated with caring are likewise part of women’s accepted social roles in many cultures worldwide (Cancian & Oliker, 2000). Women are traditionally viewed as “kin-keepers and care providers,” shaped not only by familial experiences and expectations but societal expectations and gender norms (Aronson, 1992; Fleming & Agnew-Brune, 2015; Gaugler et al., 2008; Moen, Robison, & Dempster-McClain, 1995, pp. 259). Nevertheless, approximately 40% of the caregivers in the United States are men, which means there are around 16 million male caregivers in the United States, and this number is increasing (Accius, 2017; National Alliance for Caregiving, 2015).

There is a small but growing literature on gender differences in caregiving, yet evidence is mixed regarding the impact of caregiving on psychological outcomes. A literature review by Li et al. (2013) found that although caring for a spouse affects males and females differently, both male and female spouse caregivers are affected by secondary stressors (e.g., relationship, lifestyle, sleep, finance). Female spouse caregivers of cancer patients, compared with male spouse caregivers, have typically been found to have higher levels of stress, depression, and anxiety (Barnoy, Bar-Tal, & Zisser, 2006; Dumont et al., 2006; Kim, Loscalzo, Wellisch, & Spillers, 2006; Langer, Abrams, & Syrjala, 2003; Li et al., 2013; Morgan, Ann Williams, Trussardi, & Gott, 2016; Pinquart & Duberstein, 2005; Swinkels, Tilburg, Verbakel, & Broese van Groenou, 2019). However, other studies found that male spouse caregivers experienced higher distress (Baider, Ever-Hadani, Goldzweig, Wygoda, & Peretz, 2003; Goldzweig et al., 2009), and still others have found no gender differences in stress or anxiety (Northouse, Templin, & Mood, 2001; Oechsle, Goerth, Bokemeyer, & Mehnert, 2013). Research on factors that may mediate the relationship between caregiving and psychosocial outcomes, such as social support, is also mixed (Goldzweig et al., 2009; Northouse et al., 2001).

These differences may be a byproduct of different approaches to caregiving by men and women (Campbell & Carroll, 2007; Mott, Schmidt, & MacWilliams, 2019). Female spouse caregivers tend to complete more care tasks than male spouse caregivers (Li et al., 2013), but male caregivers are more likely than female caregivers to be employed, which can add additional strain (Accius, 2017; Navaie-Waliser, Spriggs, & Feldman, 2002). Caregiving could also be particularly challenging for male spouse caregivers, as in addition to navigating new roles (e.g., patient and caregiver) and maintaining old roles (e.g., husband and wife), they experience a shift in traditional gender roles (Russell, 2007). Evidence suggests that role conflict such as this can cause stress and lower an individual's level of psychological well-being (Burke & Stets, 2009; Hecht, 2001). Men's gender role conflict, more specifically, has been linked to depression, substance abuse, and relationship issues (O'Neil, 2015). Male spouse caregivers appear to take on a more intensive caregiving role compared with other types of male caregivers, such as brothers or sons (Accius, 2017; Wagner, Bigatti, & Storniolo, 2006), providing care for a longer period of time, and assisting with more activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (Accius, 2017). Rather than reflecting only gender, kinship ties and obligations that accompany aspects of gender play an important role in the performance of care (Comas-d'Argemir & Soronellas, 2019). Understanding the many complex interrelationships between people, context, and the cancer trajectory adds to an expanded conceptual model of the cancer family caregiving experience proposed by Fletcher, Miaskowski, Given, and Schumacher (2012). In using this conceptual model, we do not limit ourselves to a single theory. Rather, we hope to understand advanced cancer caregiving in a more holistic manner.

More research has been called for that specifically focuses on variations in the caregiver experience and how these are influenced by factors such as gender (Stenberg et al., 2010). Additionally, most previous work focuses on patients and caregivers with early-stage cancers. There is a growing literature on caregiving in the advanced or life-limiting cancer context (Dionne-Odom et al., 2019; Dumont et al., 2006; Grov, Dahl, Moum, & Fosså, 2005) yet more research is needed, especially on the differential impacts of caregiving based on gender (Allen, 1994; Stenberg et al., 2010). For instance, work conducted by Dionne-Odom et al. (2019) articulates the ways in which family caregivers assist their advanced cancer patients with healthcare decision-making; this is an important addition to the literature, but other than highlighting that most caregivers in their sample are female (95%), there is no discussion about gender. Given the limited work and inconsistent findings regarding gender differences in spouse caregivers of cancer patients, our goals are threefold: (1) to identify potential differences in the amount of spousal caregiving provided by males and females; (2) to examine how gender influences caregiver stress, burden, anxiety, and depression as well as patient psychosocial outcomes; and (3) explore how caregiver gender influences coping styles.

Methods

This was a secondary data analysis of questionnaire data completed at a single time point by advanced cancer patients and their spouse caregivers as part of a larger study of naturalistic patient-caregiver communication (Reblin et al., 2018).

Participants

Patients at a large NCI-designated Comprehensive Cancer Center were screened for eligibility criteria using clinic schedules and medical records. Inclusion criteria for patients included a diagnosis of stage III or IV non-small cell lung or pancreatic, esophageal, gastric, gallbladder, colorectal, hepatocellular, or bile duct cancer; Karnofsky Performance Status (Peus, Newcomb, & Hofer, 2013) scores of 70+ (i.e., able to care for self, but normal activity may be limited); a prognosis of more than 6 months; and undergoing active treatment at the Cancer Center. Inclusion criteria were selected to identify advanced cancer patients with high enough functional status to complete the aims of the primary study, which involved a full day of study-related activities. Patient participants had a cohabiting spouse/partner who identified as providing some care and also agreed to participate. Both patient and caregiver were required to be over 18 years of age and English-speaking/writing. Participants were approached in clinic; study staff verified eligibility and obtained informed consent from each patient and spouse that wished to participate.

Measures

Patients and caregivers separately completed questionnaires on demographic and health factors, including the amount of time spent caregiving and the number of ADLs/IADLs caregivers assisted with. Both patients and caregivers also completed the following psychosocial measures. For all measures, higher scores indicate higher levels of the construct.

Hospital Anxiety and Depression Scale (HADS)—The HADS is a 14-item scale capturing state anxiety and depression. Each item on the questionnaire is scored from 0 to 3 (no to high anxiety); a summed score is calculated for each 7-item subscale between 0 and 21. This scale has been validated among cancer family caregivers in both screening and research (Bjelland, Dahl, Haug, & Neckelmann, 2002).

Perceived Stress Scale—The 4-item Perceived Stress Scale (Cohen, 1988; Cohen, Kamarck, & Mermelstein, 1983) was used to capture baseline stress levels for patient and caregiver. This scale has previously been used in cancer patients (Golden-Kreutz, Browne, Frierson, & Andersen, 2004) and caregiver populations (Kessler et al., 2014).

Caregiver Burden Scale—Caregiver burden was assessed for caregivers only using the Caregiver Burden Scale, a 14-item survey that measures the impact of caregiving on three dimensions of burden: objective, subjective demand, and subjective stress (Montgomery, Gonyea, & Hooyman, 1985a; Montgomery, Stull, & Borgatta, 1985b). *Objective burden* is defined as the perceived interruption of the tangible aspects of a caregiver's life (Ferrell & Mazanec, 2009). *Subjective demand burden* is the caregiver's perceived demands of caregiving responsibilities (Ferrell & Mazanec, 2009). *Subjective stress burden* is the caregiver's perceived emotional response to the caregiving responsibilities (Ferrell & Mazanec, 2009; Montgomery, Stull, et al., 1985b). The ordinal scale ranges from 1 (a lot less) to 5 (a lot more). Cut-off scores were established for each of the burden dimensions, with Objective Burden scores of > 23, Subjective Demand Burden score of > 15, and Subjective Stress Burden score of > 13.5 indicating higher levels of burden (Montgomery, Stull, et al., 1985b).

Duke Social Support and Stress Scale (DUSOCS)—The DUSOCS (Parkerson, Broadhead, & Tse, 1991; Parkerson Jr. et al., 1989) includes subscales for network social support and network social stress. Over 12-items, respondents use a 3-point scale (*none* to *a lot*) to rate people who give personal support and people who cause stress.

Coping Self-Efficacy Scale (CSE)—The CSE (Chesney, Neilands, Chambers, Taylor, & Folkman, 2006) is a 13-item scale used to measure confidence in performing coping behaviors under stress. There are three subscales: using problem-focused coping (6 items), stopping unpleasant emotions and thoughts (4 items), and getting support from friends and family (3 items).

Communication and Attitudinal Self-Efficacy Scale for Cancer (CASE)—The CASE is a 12-item scale of self-efficacy to maintain productive communication and a positive attitude in the face of cancer (Wolf, Chang, Davis, & Makoul, 2005). The scale consists of three, 4-item subscales: understanding and participating in care, maintaining a positive attitude, and seeking and obtaining information.

Preparedness subscale of the Family Care Inventory—Preparedness for caregiving was assessed for caregivers only and was measured by the 8-item Preparedness subscale of the Family Care Inventory, which assesses the perceived level of preparation for various facets of caregiving such as dealing with physical needs and emotional problems (Archbold, Stewart, Greenlick, & Harvath, 1990). A five-point Likert-type scale is used ranging from 0 (not at all prepared) to 4 (very well prepared). The scale also assesses previous caregiving experience.

Couples Satisfaction Index (CSI)—Relationship satisfaction was measured using the 4-item CSI where participants respond using a 6-point Likert-type scale (Funk & Rogge, 2007). The CSI discriminates between distressed and non-distressed relationships (Funk & Rogge, 2007) and a meta-analysis found excellent reliability (range 0.90–0.98) and an average Cronbach's alpha of 0.94 (Graham, Diebels, & Barnow, 2011).

Analysis

Descriptive analysis was conducted on all measures, as shown in Table 1, using IBM SPSS 25 (IBM Corp., 2017). Significance for all analyses was specified at $\alpha = 0.05$ (two-tailed).

Differences in quantitative variables were analyzed using *t*-tests. Categorical variables were analyzed by a Chi square test (Polit & Beck, 2008).

Results

Eighty-eight spouse caregivers ($n = 63$ women, $n = 25$ men) of patients with stage III or IV cancer participated in this study. Although this study was open to all sexual orientations, our study sample consisted of only heterosexual spousal couples. The sample consisted of older adults with an average caregiver age of 65 (SD = 9.4) and patient age of 66.8 (SD = 9.2). The average number of years married was 34 (SD = 15.7). The sample was predominantly white (90% of caregivers, 93% of caregivers). See Table 1 for demographics and descriptive statistics for patients and caregivers separated by gender.

There were no significant gender differences for patient or caregiver demographics, including race/ethnicity, education, religion, employment, financial situation, income, insurance, age, years married, number of people living in the home, and medical history. There were no differences in caregiving variables, such as the number of ADLs, years caregiving, or hours of care provided per week. Caregivers reported caring for their spouse on average between 4.4 months (female) and 5.6 months (male) prior to the study, for an average of 10 h (female) to 12.7 h (male) per week. Although there were no significant gender differences in caregiving tasks assessed through ADLs and IADLs, Fig. 1 shows which caregiving tasks spousal caregivers reporting doing and not doing. Male spouse caregivers and female spouse caregivers also did not differ in terms of caregiver burden (demand, objective, or stress burden). However, female spouse caregivers reported significantly higher levels of perceived stress ($t = -2.26$, $p < 0.05$), depression ($t = -2.90$, $p < 0.01$), and anxiety ($t = -2.85$, $p < 0.01$) compared with male spouse caregivers. Patient perceived stress, anxiety, and depression were not significantly different based on the gender of the caregiver.

There were no significant differences in caregiver self-efficacy for coping (CSE) or communication (CASE), social support, or preparedness for caregiving. However, female patients of male spouse caregivers were found to be more likely to use social support as a coping style than male patients with female spouse caregivers ($t = 1.99$, $p < 0.05$). Male patients also reported significantly higher satisfaction with their relationships with their caregivers than did female patients ($t = 7.872$, $p < 0.05$).

Discussion

Our first goal was to identify potential differences in the amount of time and type of caregiving provided by males and females. We found no gender differences, which is consistent with other findings (Neal, Ingersoll-Dayton, & Starrels, 1997; Ussher & Sandoval, 2008). However, our results stand in contrast to other research which has reported that women spend more time caregiving and take on more caregiving tasks (Gaugler et al., 2008; Morgan et al., 2016; Navaie-Waliser et al., 2002). One potential reason for the lack of observed gender differences in the amount of time spent caregiving is that there were no significant differences in the employment status of male and female caregivers. Men are generally more often employed outside the home (Bureau of Labor Statistics, 2019), but the relatively similar employment rates in our sample, combined with the low rates of full-time work across genders, could lead to more equitable amounts of time available to spend providing care. However, the overall reported amount of time spent caregiving, along with number of caregiving tasks, was relatively low. Although the patients in our study were selected to be relatively high-functioning, the low amount of time reported caregiving is somewhat surprising given that patients were all in an advanced stage of cancer. National statistics indicate that cancer caregivers report spending, on average, approximately 33 h caregiving per week (National Alliance for Caregiving, 2016). Spouse caregivers in this study reported spending an average of 11.2 h per week on caregiving activities, yet a wide range was also reported (0–70 h per week). This may be due to the proximity of the "time spent caregiving" question to the question about caregiving tasks, which were specifically focused on ADLs and IADLs. In a study of informal caregivers of people with chronic illnesses (55% of the sample cared for their spouse/partner), which evaluated and measured ways of recording informal care tasks, participants reported spending 5.8 h per day performing ADLs, IADLs, and housework (Van den Berg & Spauwen, 2006). However, caregiving tasks can also encompass emotional work, such as providing emotional support, or tasks such as information-seeking, communicating updates or coordinating visits from friends and family, and logistics, such as scheduling appointments. Spouses, and maybe wives in particular, may include these caregiving tasks in their normal expectations of being a spouse (Williams, Giddings, Bellamy, & Gott, 2017). This is echoed by research that shows that spouses often do not identify as caregivers (Allen, Goldscheider, & Ciambrone, 1999; Williams et al., 2017).

Our second goal was to examine how gender influences caregiver stress, burden, anxiety, and depression as well as patient psychosocial outcomes. We found that, despite no significant differences in reported amount of caregiving, female spouse caregivers reported more stress, depression, and anxiety compared with male spouse caregivers. Prior studies demonstrate mixed findings as to gender differences in the caregiver experience (Li & Loke, 2013; Li et al., 2013). Yet, our findings align with numerous prior studies indicating females experience more stress, anxiety, and depression (Barnoy et al., 2006; Dumont et al., 2006; Kim et al., 2006; Langer et al., 2003; Pinquart & Duberstein, 2005). It is not clear if this gender difference exists due to primary stressors, such as patient illness related factors, or secondary stressors, such as role change or financial distress (Fletcher et al., 2012).

This finding may have direct impacts on our third goal, which was to explore if caregiver gender influenced coping styles. Although we found no gender differences in caregiver coping strategies, this may suggest that the impact of caregiving on women is more complicated than what was assessed with our measures; this calls for a closer look at cognitive and behavioral responses to a cancer diagnosis and caregiving through the lens of gender (Fletcher et al., 2012). Considering our results that female patients of male spouse caregivers were more likely to use social support as a coping style than male patients with female spouse caregivers, more work is needed to untangle the ways in which gender affects caregivers and coping.

It may be argued that quantitative measures are not accurately capturing the caregiver experience. How do we reconcile our female participants' reported anxiety, depression, and stress with their relative lack of reported caregiver burden? The broader health literature suggests that women's traditional orientation to a more communal ("other-focused" versus "self-focused") self-representation and increased sensitivity to relationship cues may impact their caregiving experience and increase their risk for negative health outcomes, such as depression (Kiecolt-Glaser & Newton, 2001). Although there were no differences in male and female caregiver self-reported relationship satisfaction, we did not assess relationship expectations. The way people think about their relationships can have an important impact on their health and well-being (Robles, 2014). Because caregiving is part of an expected social role that women are assumed to perform, there is a decreased desire to describe caregiving as burdensome, similar to the underreporting of some behaviors due to perceived social stigma and the desire to portray oneself positively (Bharadwaj, Pai, & Suziedelyte, 2017). Role theory suggests "humans act in varying and predictable ways based on the expectations and conditions of the social role they are assuming" (Bastawrous, 2013, p. 435; Biddle, 1986). The Caregiver Burden Scale may not accurately reflect *actual* burden because women understand their social role and do not wish to be seen as unhappy with their "expected and natural" social role. In other words, societal expectations can impact a person's perceptions of what is normal and acceptable, and the scales we used may be assessing perceived versus actual burden. Measures such as ADLs and IADLs may capture more traditionally "male" tasks such as transferring and walking (requiring physical strength on the part of the caregiver) or managing finances (Campbell & Carroll, 2007; Mott et al., 2019). However, in research on household division of labor, women have been found to bear more of the "mental load," as they are responsible for not only completing more tasks, but also managing, planning, and organizing the household tasks (Lachance-Grzela & Bouchard, 2010). Female spouse caregivers may be similarly shouldering a greater mental load in caregiving, impacting their psychosocial outcomes. Future research should capture both physical *and* emotional caregiving tasks and use multiple methods to avoid self-report bias, particularly because objectively measured behaviors explained considerably more of the variance than self-report data among women compared with men (Kiecolt-Glaser & Newton, 2001).

Interestingly, in our analysis of patient data we found that, consistent with assumed U.S. gender roles, female patients used social support as a coping mechanism more than male patients did. One limitation of our study is that we did not assess the larger caregiving network that normally surrounds a person, and instead focused on one primary caregiver. Female patients' greater use of social support may lower the caregiving demand on male spouse caregivers. Women tend to have a larger, female-oriented social network, which may decrease burden on their primary male caregiver (Sims-Gould, Martin-Matthews, & Rosenthal, 2010). This would potentially reflect the greater levels of stress, anxiety, and depression that were found in female spousal caregivers, as their spouses rely primarily on them for support rather than a wider network of people. This could also indicate that female patients of male spouse caregivers may not be receiving the "social" aspect of caregiving, which is reflected in the work of male caregivers focusing on the "masculine" aspects of caregiving (Mott et al., 2019).

Limitations

This study was a secondary analysis of data. As a result, important variables such as role change, utilization of support resources, and social identity were not captured. Additionally, this study did not have enough power to assess if some measures either explain (e.g., mediate) or alter (e.g., moderate) the effect gender may have on these outcome measures. Furthermore, our sample consists of heterosexual, racially-homogeneous, and mostly mid-life to older adults drawn from a single institution and may not be generalizable to more diverse samples. Future studies in advanced cancer caregiving should focus on other subpopulations to understand the vast array of lived experiences.

Conclusion

Our study is one of the first to assess potential gender differences in caregiving activities, psychosocial outcomes, and coping among spouse caregivers in an advanced cancer population. The importance of understanding differential caregiver experience along the cancer trajectory is important, and our findings have clinical implications for the health system more broadly and those treating cancer patients more specifically. Our findings echo previous research that indicates that cancer caregivers report high levels of distress (Girgis et al., 2013; Sklenarova et al., 2015). Caregiving stress has been shown to impact psychological and physiological health and even mortality (Teixeira, Remondes-Costa, Graça Pereira, & Brandão, 2019); further, the mechanisms by which stress impacts men and women may differ (Espnes & Byrne, 2008; Taylor et al., 2000). Thus, it is important for health systems to attend to those providing care, especially as the numbers of family caregivers increase with an aging population. More specifically, providers of advanced cancer patients should focus on caregivers stress given that caregiver well-being also predicts patient perception of quality of care (Litzelman, Kent, Mollica, & Rowland, 2016) and increased patient hospital admission and longer hospital stays, often due to inability to manage patient symptoms (Ankuda et al., 2017; Bonin-Guillaume et al., 2015; Dionne-Odom et al., 2016). Female caregivers, in particular, may need additional screenings or psychological support to address their increased levels of stress, anxiety, and depression experienced during the caregiving process. Caregiver stress can also be distressing for patients and have impacts on their health, so interventions designed to improve caregiver health should be included in holistic patient care (Kim, Carver, Shaffer, Gansler, & Cannady, 2015; Litzelman & Yabroff, 2015; Waldron, Janke, Bechtel, Ramirez, & Cohen, 2013). We urge researchers to consider gender more explicitly when assessing cancer caregivers and to use measures that more accurately assess potential differences. Just as biomedical researchers have begun to understand the impact that sex can have on disease phenotypes in animal research, and thus the need to explicitly state sex in their materials and methods (Flórez-Vargas et al., 2016), social science researchers must not assume that gender makes no difference in caregiving. A movement towards gender-sensitive models of both research and interventions and away from generalized models is needed (Gabriel, Beach, & Bodenmann, 2010). In moving forward, we echo the work of Fletcher et al. (2012) who call for the stress process and cancer trajectory to be embedded within the larger context of cancer caregiving. To accomplish this methodological and theoretical aim, researchers should employ multiple methods to fully understand the caregiver experience.

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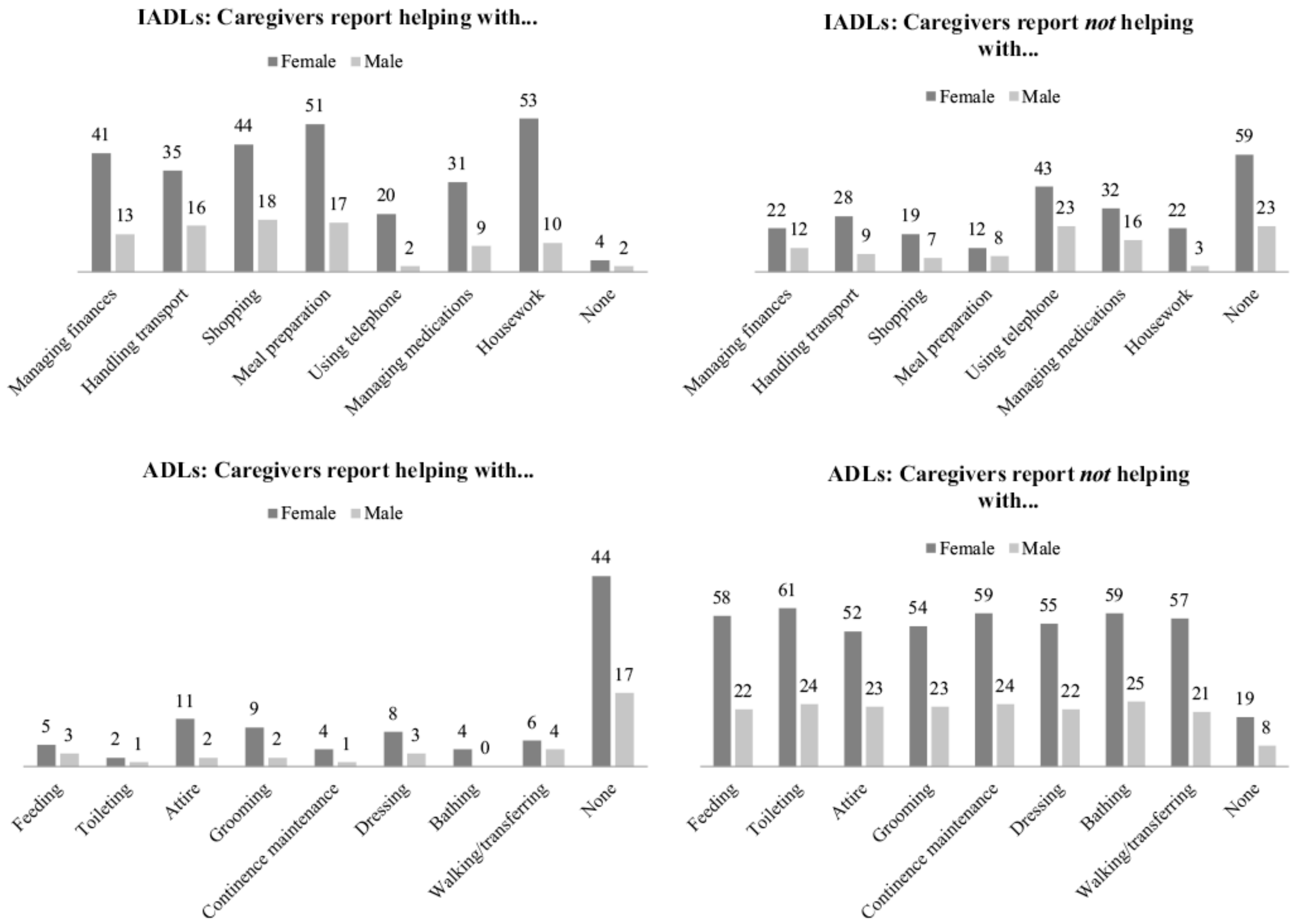

Fig. 1.

Number of caregivers who report ADL and IADL help or not

Table 1

Participant characteristics and measures

Characteristic	Number of participants (%)/mean (range)									
	Caregiver			Statistic	*p* value	Patient			Statistic	*p* value
	Male	Female	Total			Male	Female	Total		
Demographics										
Gender	25 (28.4)	63 (71.6)	88 (100)			63 (71.6)	25 (28.4)	88 (100)		
Age	66.5 (47–84)	64 (39–80)				65 (45–78)	67.5 (44–89)			
Length of relationship	34.5 (2–58)	33.9 (1–64)		0.15	0.8796	35 (8–58)	33.8 (1–64)		0.33	0.7419
Race										
AI/AN	0	2 (2.3)	2 (2.3)			0	1 (1.1)	1 (1.1)		
White/Caucasian	22 (25.0)	57 (64.8)	79 (89.8)			24 (27.3)	58 (65.9)	82 (93.2)		
African–American	1 (1.1)	3 (3.4)	4 (4.5)			1 (1.1)	4 (4.5)	5 (5.7)		
Other	1 (1.1)	0	1 (1.1)			0	0	0		
Ethnicity										
Non-Hispanic	24 (27.9)	57 (66.3)	81 (94.2)	0.2118	1	25 (28.4)	60 (68.2)	85 (96.6)	1.2325	0.2669
Hispanic	1 (1.2)	4 (4.65)	5 (5.8)			0	3 (3.4)	3 (3.4)		
Religious affiliation										
Catholic	7 (8.4)	14 (16.9)	21 (25.3)	0.9556	0.9165	5 (6.0)	14 (16.9)	19 (22.9)	4.2076	0.3786
Jewish	1 (1.2)	4 (4.8)	5 (6.0)			1 (1.2)	3 (3.6)	4 (4.8)		
Protestant	9 (10.8)	23 (27.7)	32 (38.6)			13 (15.7)	22 (26.6)	35 (42.2)		
Other	4 (4.8)	11 (13.3)	15 (18.1)			4 (4.8)	8 (9.6)	12 (14.5)		
No religious affiliation	4 (4.8)	6 (7.2)	10 (12.1)			1 (1.2)	12 (14.5)	13 (15.7)		
Financial situation										
Not very good	3 (3.5)	7 (8.1)	10 (11.5)	0.0715	0.9649	2 (2.4)	9 (10.6)	11 (12.9)	0.6358	0.7277
Comfortable	17 (19.5)	41 (47.1)	58 (66.7)			15 (17.7)	35 (41.2)	50 (58.8)		
More than adequate to meet my needs	5 (5.8)	14 (16.1)	19 (21.8)			7 (8.2)	17 (20.0)	24 (28.2)		
Education										
Less than high school	1 (1.1)	1 (1.1)	2 (2.3)	7.1088	0.2127	0	3 (3.4)	3 (3.4)	8.0048	0.156
High school graduate or equivalent	4 (4.6)	10 (11.4)	14 (15.9)			7 (8)	6 (6.8)	13 (14.8)		
Some college or vocational school	6 (6.82)	26 (29.6)	32 (36.4)			7 (8)	22 (25.0)	29 (32.9)		

Characteristic	Number of participants (%)/mean (range)									
	Caregiver			Statistic	*p* value	Patient			Statistic	*p* value
	Male	Female	Total			Male	Female	Total		
College graduate (4 years)	5 (5.7)	8 (9.1)	13 (14.8)			2 (2.3)	14 (15.9)	16 (18.2)		
Some graduate or professional school	0	6 (6.82)	6 (6.8)			2 (2.3)	5 (5.7)	7 (8)		
Graduate or professional degree	9 (10.2)	12 (13.6)	21 (23.9)			7 (8)	13 (14.8)	20 (22.7)		
Employment										
Not currently employed	15 (17.7)	38 (44.7)	53 (62.4)	0.8182	0.6643	23 (26.4)	44 (50.6)	67 (77.0)	4.7772	0.0918
Part-time	2 (2.4)	9 (10.6)	11 (12.9)			0	5 (5.8)	5 (5.8)		
Full-time	7 (8.2)	14 (16.5)	21 (24.7)			2 (2.30)	13 (14.9)	15 (17.2)		
Overall health										
Excellent	2 (2.3)	12 (13.6)	14 (15.9)	3.5583	0.3133	3 (3.4)	1 (1.1)	4 (4.6)	6.5578	0.1612
Very good	14 (15.9)	24 (27.3)	38 (43.2)			9 (10.2)	23 (26.1)	32 (36.4)		
Average	8 (9.1)	26 (29.6)	34 (38.6)			9 (10.2)	19 (21.6)	28 (31.8)		
Poor	1 (1.1)	1 (1.1)	2 (2.3)			3 (3.4)	18 (20.5)	21 (23.9)		
Very poor	0	0	0			1 (1.1)	2 (2.3)	3 (3.4)		
Psychosocial measures										
HADS										
Anxiety	5.8 (0–16)	8.6 (0–19)		−2.85	0.0054	5.0 (0–12)	5.2 (0–13)		−0.28	0.7817
Depression	3.3 (0–9)	5.3 (0–15)		−2.9	0.0051	4.4 (0–12)	4.8 (0–14)		−0.65	0.5151
Total	9.0 (0–23)	13.9 (1–32)		−3.39	0.0012	9.3 (1–22)	10.0 (1–26)		−0.51	0.6123
Perceived Stress Scale	4.7 (1–9)	6.3 (0–13)		−2.26	0.026	4.0 (0–11)	4.7 (0–12)		−0.91	0.3659
Caregiver burden										
Objective burden	21.5 (17–29)	22.3 (14–30)		−0.95	0.3464					
Stress burden	13.5 (8–16)	14.3 (8–20)		−1.7	0.0945					
Demand burden	11.8 (4–18)	11.8 (4–19)		−0.07	0.9453					
DUSOCS										
Social support	11.1 (5–18)	11.7 (5–20)		−0.722	0.473	13.5 (9–18)	12.1 (5–20)		1.498	0.138
Social stress	2.2 (0–8)	2.9 (0–7)		−1.579	0.118	1.7 (0–5)	1.7 (0–10)		−0.114	0.910
Coping self-efficacy										
Problem focused	52.9 (34–70)	49.9 (17–70)		1.01	0.315	54.8 (0–32)	52.2 (4–70)		0.82	0.4148
Emotion focused	24.4 (8–40)	22.7 (0–40)		0.7	0.4837	29.6 (7–40)	29.4 (4–40)		0.28	0.7829

Characteristic	Number of participants (%)/mean (range)									
	Caregiver			Statistic	*p* value	Patient			Statistic	*p* value
	Male	Female	Total			Male	Female	Total		
Social support	20.6 (11–30)	19.9 (2–30)		0.48	0.6297	25.0 (14–30)	21.8 (0–30)		1.99	0.0496
Total	91.9 (60–130)	87.0 (25–130)		0.87	0.3864	102.4 (54–130)	96.0 (20–130)		1.11	0.2691
CASE										
Participate in care	13.4 (10–16)	13.5 (9–16)		−0.21	0.8358	14.8 (11–16)	13.6 (10–16)		1.56	0.123
Positive attitude	12.8 (9–16)	11.8 (4–16)		1.69	0.0956	13.5 (11–16)	13.0 (4–16)		1.03	0.3052
Seek information	13.7 (12–16)	13.7 (8–16)		0.08	0.9365	14.0 (10–16)	13.2 (7–16)		1.59	0.1146
Preparedness-Family Care Inventory	21.3 (10–31)	21.4 (5–32)		−0.05	0.9606					
Couples Satisfaction Index	20.2 (13–24)	20.6 (13–24)		0.139	0.617	21.3 (17–24)	19.16 (7–24)		7.872	0.022