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Meeting the Needs of Male Caregivers by Increasing Access to Accountable Care Organizations

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Introduction

Between 1987 and 1997, the percentage of informal male caregivers of older adults increased from 25 to 28 percent, respectively (Wagner, 1997), and in 2009 this percentage increased to 33 compared to 67 percent of women (National Alliance for Caregiving (NAC) & AARP, 2009). As a result of the increase in percentages, male caregivers have become more visible, which has likely contributed to the growth of fact sheets, articles, and websites geared to male caregivers, highlighting the challenges men face in caregiving to audiences including service providers and researchers (Bennett, 2012; Ginzler, 2010; Homewatch Caregivers, 2014). While the assumption is that male caregivers are uniquely different from female counterparts on account of their gender, some analyses suggest otherwise. Schwartz (2013) found overall that men's experiences in caregiving were not uniquely different from women's, and most apparent were the intragroup differences among male caregivers. For example, men who provided more hours of care and activity of daily living and instrumental activity of daily living (ADL/IADL) support to a loved one had greater odds of experiencing higher emotional stress and physical strain than men providing less care hours and fewer ADL/IADL supports (Schwartz, 2013). These findings speak to intragroup differences among men, but also highlight how, like women, men do experience emotional stress and strain under certain conditions, as discussed in a later section.

Social Construction of Gender

Gender is a process. Through interactions with others throughout life, individuals adopt characteristics that are perceived as aligned with their gender (Wharton, 2012). In these interactions, "individuals learn what is expected, see what is expected, act and react in expected ways, and thus simultaneously construct and maintain the gender order" (Lorber,

1994, p. 33). As the socialization of gender takes place over the course of one's lifetime, the gender roles individuals learn carry into later life and in the context of caregiving.

Females have traditionally assumed the role of caregivers (Kramer, 2005); therefore, "caring" is predominantly associated with femininity (Mathiowetz & Olikier, 2005). However, as a result of the increased role of women in the workforce, changing family structures (e.g., decreases in child bearing), and men and women agreeing that "traditional" gender roles as breadwinner and caretaker, respectively, are changing (Galinsky, Aumann, & Bond, 2011; Hooymann & Gonyea, 1999; Kramer, 2005), traditional gender roles do not necessarily apply to all care contexts. As a result of this evolution in gender roles (Galinsky, Aumann, & Bond, 2011; Wharton, 2012), there exists a tension between traditionally defined gender roles in "caring" as they relate to men.

Generational of Gender

An important consideration in addition to the socialization of gender is the impact of one's generation on his or her beliefs and roles in providing care. McDaniel (2004) calls this "generational gender." She argues that like gender socialization, generational is a process of learned behavior from those an individual has contact with over the life course.

Generational is accomplished:

in caring for our children in ways evocative of the ways we were raised ... caring for aging parents or when they visit us as adults and we fall immediately into the well-known cadence of the child/parent relationship. Interactions among family members of different ages ... are affirmations of symbolic enactment of generation, or ... expectations of what generation is, should be, or might be

(McDaniel, 2004, p. 31).

In work examining spousal caregivers, so as to provide the best care to their loved ones, caregivers moved beyond traditional gender roles (Calasanti & Bowen, 2006). This suggests that the shared history of the dyads is important, which also speaks to the generational of gender. This also alludes to potential age cohort differences in what it means to be "male," (Mathiowetz & Olikier, 2005), thus speaking to the differences in socialization of gender over time.

Men as "Outside" the Service System

While the present article focuses on male caregivers, the authors are not suggesting that female caregiver needs do not warrant attention, as society remains male-oriented, with women continuing to experience inequalities in earned wages as one example (Hegewisch & Ellis, 2015). However, we maintain that the service system is not prepared to address *all* caregiver needs. Despite the increased visibility of male caregivers, Kaye & Crittenden (2005) explain how "the configuration of social services is one that may not necessarily be 'male friendly' ... Services are often not designed to reach out to older male clients and older men may see seeking out services as admitting personal weakness" (p. 100). This is one reason why women more often receive supports and services than men, while men remain "outside" of the service system. Furthermore, men have been reported as being "wary" of formal support services (Zodikoff, 2007) and utilizing informal supports (e.g., unpaid help)

(Schwartz, 2013). Yet, other findings indicate that men are open to utilizing formal services (e.g., support groups, care management assistance, pain management for loved ones) (Brazil, Thabane, Foster, & Bédard, 2009; Metlife, NAC, & The Center for Productive Aging, 2003). Therefore, much like the dynamic nature of the socialization and generationing of gender, there exists a lack of consistency in the application of male caregiver data to meet their needs and incorporate men into the service system. However, the development of male caregiver-centered services and conferences (Hutchinson, 2005; The HSC Foundation, 2008) suggests that in addition to becoming more visible, male caregiver needs are beginning to be recognized by the service system, and that health care professionals have the opportunity to provide more comprehensive services that include men, while simultaneously meeting all caregiver needs.

This commentary presents the commonalities in caregiver experiences regardless of gender that matter for all caregiver well-being, while highlighting how men remain “outside” the service system. Inclusivity of male caregivers not only ensures the provision of support to all caregivers, but also ensures better quality care to care recipients who are most often women (NAC & AARP, 2009). Therefore, by assisting the caregiver, the care recipient may have better health and/or mental health-related outcomes, supported further by research reporting positive associations between caregiver and care recipient mental health outcomes (Milbury, Badr, Fossella, Pisters, & Carmack, 2013). Thus, by bringing “men” inside of the service system, not only are all caregivers receiving support, but such support can result in better health of the care recipient. However, the question remains as to how to incorporate male caregivers into the service system.

A way to establish more inclusive programs and policies for caregivers currently and in the future, and the inclusion of men, is discussed in this commentary through the use of Accountable Care Organizations as an example. Accountable Care Organizations (ACOs), coordinated care systems for Medicare patients, could incorporate men into ACO systems to provide support that could assist them in caregiving.

What is the Male Caregiver Experience?

There exist contextual differences that impact caregiver experiences, with gender being only one factor. Robinson, Bottorff, Pesut, Oliffe, and Tomlinson (2014) completed a comprehensive review of research concerning male caregivers of relatives with dementia, which aligns with contemporary and earlier research reporting that male caregivers experience less burden (e.g., depression) than female counterparts (Akpınar, Küçükgüçlü, & Yener, 2011; Campbell et al., 2008; Papastavrou, Tsangari, Kalokerinou, Papacostas, & Sourtzi, 2009). However, in light of the socialization and generationing of gender, men experiencing less emotional stress than women does not account for intragroup differences among male caregivers. As previously stated, Schwartz (2013) found an association between men providing more hours of care and ADL and IADL support with greater odds of experiencing higher emotional stress and physical strain. This finding is aligned with Pinquart and Sörensen’s (2006) suggestion based on their meta-analysis, that negative impacts experienced by caregivers are more likely related to a loved one’s care needs (as one example) than caregiver gender. Other intragroup differences among men have included

co-residing with the care recipient being associated with a greater likelihood of greater physical strain, compared to men not co-residing with the care recipient (Schwartz, 2013). These findings relate to results from a largely based female sample of spousal/adult child caregivers or caregivers who did or did not co-reside with a loved one, and how these elements are important considerations in understanding caregiver well-being (Berg-Weger, McGartland, Rubio, & Tebb, 2000). This alludes to the generation of gender and what individuals perceive as appropriate care patterns based on what is modeled by those in their family. Caregiver employment status is another important consideration. While Duxbury, Higgins, and Smart (2011) found that female employed caregivers had higher physical and emotional strain than male counterparts, employed male caregivers have reported almost the exact same percentages of negative consequences associated with caregiving as women (e.g., impact on relationships) (MetLife, NAC, & The Center for Productive Aging, 2003). Amount of care being provided, dyad relationship type, and caregiver employment status are just a few examples of the various contexts of caregiving that impact an individual's experience in the care role, and the overlaps in male and female caregiver experiences.

Formal and Informal Service Use by Male Caregivers

Understanding what is currently known about male perceptions and utilization of informal and formal supports is crucial to inform and develop programs that bring men into the service system. Informal supports refer to family members and friends, while formal supports are paid community-based services (e.g., home care, transportation, respite). Some research indicates that men have greater odds of using unpaid help (e.g., family and/or friends) than women (Schwartz, 2013) and prefer assistance from informal rather than formal support (Stommel, Collins, Given, & Given, 1999). Although men may more readily accept informal help, asking for help has been associated with the concern that family or friends do not have time to provide assistance, and/or men feeling it is their responsibility to provide care (Sanders, 2007). On the contrary, other research has reported a disconnect between the type of informal support men desire versus what was being offered to them. For example, Eriksson, Sandberg, and Pringle (2008) found that informal supports assumed male caregivers needed assistance with household duties, a typically "female" task; however, the men did not desire such help. Thus, when informal support is available, it does not mean that it will meet the needs of the male caregivers, and what is offered may be based on gender stereotypes, further alluding to the changing meaning of and socialization of gender.

Men have reported being less confident about formal services (Zodikoff, 2007), have indicated experiencing problems in obtaining services, supports, and information (Coe & Neufeld, 1999; Neufeld & Kushner, 2009), and have associated accepting formal supports with being an inadequate caregiver (Coe & Neufeld, 1999; Kaye, 2005; McFarland & Sanders, 1999). However, men have reported the use of some types of formal support (e.g., homemaking, transportation) (Brazil et al., 2009; Schwartz, 2013; Sun, Roff, Klemmack, & Burgio, 2008). To the authors' knowledge, the help-seeking behaviors of men couched in contemporary understandings of the socialization of gender and the meaning of masculinity remain understudied, and are warranted to gain a more holistic picture of men's acceptance of formal supports.

The “Male Approach” to Caregiving

Men have described using a managerial and task-oriented approach to caregiving, and framing the role of caregiver as a “job” (Calasanti & King, 2007; McFarland & Sanders, 1999; Pretorius, Walker, & Heyns, 2009; Russell, 2001, 2007). Kaye and Crittenden (2005), indicate “men prefer opportunities to problem-solve and gather information about a topic as well as serve as ‘expert’ to other men” (p. 117). Russell (2004) and Eriksson et al.’s (2008) work perpetuates Kaye and Crittenden’s statement, as they found that their male caregiver participants would meet with peers as a break from caregiving, and/or opportunity to seek advice and solutions to problems in the care process. Seeking peer support is not unique to men, as this support type has also been perceived as beneficial by a mostly female caregiver sample (Abendroth, Greenblum, & Gray, 2014).

Tying Men to Supportive Services by Increasing Access to Accountable Care Organizations

With the knowledge that there are overlaps in the experiences of caregiving men and women, that men do experience challenges in caregiving, and that men remain outside of the service system, it is important to be able to provide comprehensive support services to *all* caregivers. Accountable Care Organizations (ACOs), developed under the Patient Protection and Affordable Care Act of 2010, are one vehicle to move men inside of the service system while simultaneously addressing all caregiver needs. In light of the various aging and caregiver support programs that exist, the question of what is “special” about ACOs remains. As ACOs are relatively new programs that continue to develop nationwide, and because of their flexible structure, there is an opportunity to develop these organizations in ways that are more inclusive and capture caregivers who may or may not already be receiving services to support them in the care process, including men and women alike. Although ACOs provide Medicare beneficiaries with coordinated health care (CMS, 2014a), caregivers often accompany patients to medical-related visits. Thus, not only would contacts with these organizations provide men with access to coordinated care for their loved one, but they could simultaneously serve as a point of access for caregiver information and support. ACOs could be structured to incorporate support for patients’ caregivers, while taking into account variations in caregiver experiences (e.g., employed caregivers) and providing tailored information and support based on caregivers’ particular needs.

An overview of what ACOs are, and an example of an ACO in North Carolina is utilized to illustrate how these organizations may be structured and function. We end with recommendations on how ACOs could serve as a point of access and support for male and subsequently all caregivers.

Background: ACO Structures and Development

Accountable Care Organizations (ACOs) are coordinated Medicare teams that are flexible in structure and include health care providers such as doctors and hospitals (Keckley & Hoffmann, 2010). The purpose of ACOs is to provide coordinated, high quality, and cost-effective care for Medicare beneficiaries. Care coordination is key to ensuring that Medicare

beneficiary health care needs are met without incurring additional or needless costs (e.g., repeated tests, medical procedures) (Centers for Medicare and Medicaid Services [CMS], 2014a). Providers and health care organizations are not required to develop or participate in an ACO, but if they do, they must notify their patients, who can then choose to maintain services with their provider(s) or seek health care elsewhere (CMS, 2014a).

An important aspect of ACOs is their flexible structure. In addition to physicians, the organization may decide to include other types of providers. For example, at Duke Medicine in North Carolina, physicians, nurses, health educators, pharmacists, and care managers are part of an ACO called Duke Connected Care (E. Komives, personal communication, September 15, 2014). As is the case with most ACOs nationwide, the primary point of contact for a Medicare patient in Duke Connected Care is his or her primary care physician. In some cases, a specialist may be the primary point of contact, depending on the patient's health care needs (E. Komives, personal communication, September 15, 2014).

Like other ACOs, Duke Connected Care includes care management as one of its functions. Care management encompasses both disease management and helping patients and families connect with community resources, depending on the patient's needs. Patients are identified as being appropriate for care management using indicators of risk (multiple chronic conditions, hospital admissions or frequent emergency visits) or by referral from a provider or specialist, or through self-referral (E. Komives, personal communication, September 24, 2014).

There exist four Accountable Care Organization (ACO) model types: Medicare Shared Savings Program, Advance Payment Model, Pioneer Model, and Next Generation Model. These forms differ primarily based on the financial incentives to providers. Pioneer applicants were initially chosen by the Center for Medicare and Medicaid Innovation partly based on their preexisting "ACO-like" structure and implementation of coordinated care (CMS, 2012). CMS is currently accepting applications for the Next Generation ACO model that differs from the Pioneer model in ways such as:

greater access to home visits, telehealth services, and skilled nursing facility services...opportunities to receive a reward payment for receiving care from the ACO ... [and] greater collaboration between CMS and ACOs to improve communication with beneficiaries about the characteristics and potential benefits of ACOs in relation to their care

(CMS, 2015a, ¶1).

The Medicare Shared Savings Program (MSSP) model is the most common type of ACO. Duke Connected Care is one of 405 operational MSSPs nationwide as of January 2015 (CMS, 2015b). In the MSSP model, if quality and cost savings are met, the ACO receives a percentage of the savings to be distributed among participating providers (CMS, 2014a).

The Advance Payment model is for ACOs that previously participated in the MSSP, and they receive payments prior to providing services to Medicare patients in either a lump sum or monthly payment. Advance Payment ACOs are at a greater risk of owing funds back to Centers for Medicare and Medicaid Services (CMS) if they do not produce anticipated

savings (CMS, 2014b). Two types of ACOs are eligible to apply to be an Advance Payment model: “[1.] inpatient facilities [with] less than \$50 million in total annual revenue, [or] 2. ACOs in which the only inpatient facilities are critical access hospitals and/or Medicare low-volume rural hospitals and have less than \$80 million in total annual revenue” (CMS, 2014b, p. 6).

Recommendations for Accountable Care Organization Development to Meet Male Caregiver Needs

While Accountable Care Organizations (ACOs) are centered on Medicare patients, caregivers tend to accompany loved ones at doctor and other medical-related appointments. Therefore, ACOs can serve as a point of contact for caregivers. With both patient and caregiver present, health care professionals in contact with the dyad can capture a more holistic picture of the caregiving context and appropriate health and psychosocial needs can be identified.

The Centers for Medicare and Medicaid Services (CMS) mandates that ACOs meet quality measure standards to ensure cost-efficient and quality care is provided to patients (Keckley & Hoffmann, 2010). The performance domains measured include: patient/caregiver experience, care coordination/patient safety, preventive health, and at-risk population (RTI International, 2015, pp. 3–4). The domain “patient/caregiver experience” is of particular interest to the authors based on the purpose of this paper. This domain includes 8 items: timely care, appointments, and information; how well your providers communicate; patients’ rating of provider; access to specialists; health promotion and education; shared decision-making; health status/functional status; and stewardship of patient resources (RTI International, 2015, p. 3). While the word “caregiver” is contained in one of the items, the succeeding questions are framed to assess the patient’s experience. While caregivers may be proxy respondents on behalf of patients who are unable to answer the items (E. Komives, personal communication, September 15, 2014), it is possible that proxy responses would reflect more closely the caregiver rather than the patient perspective. In reviewing the CMS quality measure documentation, there are no items that capture caregiver experiences within an ACO such as success in linking caregivers to support services. The caregiver experience in contacts with ACOs is important to understand, as caregivers tend to facilitate various aspects of a patient’s care (Mitnick, Leffler, & Hood, 2010). Four recommendations concerning increasing access for male caregivers to ACOs through subsequent program and policy developments follow based on what is understood about the male caregiver experience and information concerning ACO structures and functions. These recommendations, although framed in the context of male caregivers, would benefit all caregivers regardless of their gender.

1. Modification of Centers for Medicare and Medicaid Services (CMS) Quality Measure Assessment

Bachman (2011) argues that the inclusion of patients in Accountable Care Organization (ACO) development is paramount and that social workers should be included as a result of our valuing empowering individuals. Likewise, caregivers should also be incorporated into

the development and evaluation of ACO effectiveness. As the patient/caregiver CMS quality measure is focused predominantly on patient experiences in the ACO, further assessment of the caregiver experience is warranted. Caregiver assessment is a useful tool in providing a patient's caregiver with information and support that may result in helping them in the care process. ACOs are meant to streamline services patients receive through care coordination, and in turn reduce health care utilization based on the organizations' specific patient needs (CMS, 2011). Helping caregivers provide effective care in the home setting, can also result in the reduction of health care utilization (e.g., emergency department visits, hospitalizations), which is aligned with the basic goals of ACOs. In such caregiver assessments, questions should be added that are sensitive to the fact that caregivers are a diverse group of individuals economically, racially, ethnically, and also with regard to gender. Developing questions that capture such diversity should also account for the challenges men experience in the caregiving role and the way they approach caregiving. If caregiver assessments were to be included in ACO structures, questions could center on whether such assessments were useful in meeting male caregiver needs, in order to provide an understanding of areas of success or needed improvement in helping caregivers.

2. Caregiver Care Plan/Assessment and Mandatory Care Management Structure

Like a patient care plan, caregivers could partake in an assessment that would evaluate their needs and identify services that could be helpful to them in the care process. Doing so also provides an opportunity to support all caregivers, including men. The Family Caregiver Alliance (2006a) suggests completing assessments at points of contact with providers, such as at hospital discharge. Caregiver assessments provide the opportunity to complete "a systematic process of gathering information about a caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver" (Feinberg & Houser, 2012, p. 1). Organizations such as the Rosalynn Carter Institute for Caregiving (2004) and the Family Caregiver Alliance (2006c) provide examples of assessments, including the person completing the assessment aiding the caregiver in identifying service and emotional needs, and the provision of resource lists. The Family Caregiver Alliance (2006a; 2006b) outlines ways caregiver assessments can be structured, when and where such evaluations could occur, and the importance of policy and practice change to implement caregiver assessments. In the context of an ACO, if a patient were referred to case management, the case manager could also assess caregiver needs at the time a patient assessment occurs. This would be particularly useful for any caregivers who may be unaware of what services are available or what supports they need.

3. Mandatory Inclusion of Social Workers

As highlighted by Clark (2011), the Accountable Care Organization (ACO) final ruling includes a list of health care professionals (e.g., doctors, nurses) as ACO providers (CMS, 2011); however, social workers are not explicitly included. There has been a considerable amount of advocating to include social workers in ACOs based on their expertise and training (Andrews, Darnell, McBride, & Gehlert, 2013; Bachman, 2011; Clark, 2011; Collins, 2011) in areas such as patient navigation and care coordination (Andrews et al., 2013). Social workers should be included in ACOs because of their macro and/or micro training and sensitivity and understanding of the person-in-environment perspective

(Kondrat, 2002). As a result of their training, social workers can assist medical teams in identifying the nuances of the male and female caregiver experiences and the way to best meet needs to support all caregivers in the care process. As related to the caregiver assessment recommendation, social workers who work with older adults and caregivers would be well-positioned to view the care experience from the life course perspective, “includ[ing] exploring important roles in a man’s life in anticipation for the change in roles that accompany the aging process.” (Kaye & Crittenden, 2005, p. 101).

While some ACOs most likely have social workers, credible evidence of how extensively social workers are used is not available. Mandatory inclusion of social workers may be perceived as costly. However, based on data concerning care managers in ACO-like structures (particularly social workers), their inclusion resulted in decreased health care utilization (e.g., nursing home diversion, emergency department visits, improved treatment adherence) (Clark, 2011), which could result in decreases in costs over time. Social workers could complete the aforementioned caregiver assessments effectively based on their expertise in clinical and psychosocial health.

4. Acknowledging Male Caregivers’ Approach to Care

The HSC Foundation (2008) made recommendations on how to meet male caregiver needs, including training health care professionals about the experiences of male caregivers. As understood from the review of the literature, men approach caregiving as a “job” and are task-oriented. It is important that all ACO providers are made aware of male caregivers’ use of a task-oriented approach, and use of certain support services so that men may receive information aligned with their needs. This also presents an opportunity for social workers to be a part of the ACO team, including educating health care providers. As suggested by Kaye & Crittenden (2005), professionals’ bias can be detrimental in helping men. A core competency of social worker training is being aware of one’s own biases (CSWE, 2008). Therefore, social workers are well-positioned to educate health care professionals about gender stereotypes, and considerations about help-seeking behaviors among male caregivers.

Conclusion

With the growth of academic, caregiver, and organizational literature focused on male caregiver experiences, the challenges men face have been brought to the attention of health care professionals and the public overall. As a result of dynamic changes in health care, there is an opportunity to more successfully meet both patient and caregiver needs. Although the majority of caregivers remain female, health care professionals are not yet prepared to meet the needs of the growing number of male caregivers. As Accountable Care Organizations (ACOs) continue to develop nationwide, the aforementioned recommendations could be incorporated into these structures to ensure that patient needs and the needs of the men who care for them are met. This would result in increased access to supportive services, not just for men but for *all* caregivers regardless of their gender.

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