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Editorial Open Access

Preparing for the Aging Population: Family Caregiving and Labor Force Matters

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Editorial

The demand on the palliative care sector will rise and continue to intensify as the population ages world-wide. Many palliative care programs have shifted their emphasis to ambulatory and home-based care services to provide effective community- and team-based multidisciplinary care to individuals dying at home. Delivering care in this environment serves a dual purpose of potentially increasing the quality of life for palliative care patients, and reducing public health service expenditures related to in-patient utilization. However, the viability of this setting for care involves sharing end-of-life care costs with patients and families and relies greatly on family members or close friends to provide the majority of care [1-4]. Current research demonstrates that many caregivers of palliative care patients miss time from the labor market [1,5-9] because of their intense caregiving responsibilities in the home setting. This absence from employment has short and long term economic consequences for the caregiver as well as the labor force and society as a whole.

At the same time as growth in the demand for home-based palliative care, the aging of the population will increase the prevalence of retirement, thereby putting pressure on working-aged individuals to increase their attachment to the labor market in order to finance an array of publicly funded programs. As a result, tension will exist between the demand for unpaid caregiving within the palliative care sector and the demand for increased attachment to the labor force (i.e. participation as well as hours of work) to address labor needs. To confront this conundrum, an understanding of the influence of unpaid caregiving specifically in the palliative care context on labor force participation (LFP), including patterns and predictors of LFP, in order to formulate policy strategies that will enable individuals to provide unpaid care and either remain in the labor market or return to the labor market after an episode of caregiving. While literature addressing the labor market consequences of unpaid caregiving in general exists, a sufficient amount of research that comprehensively examines these implications in both the short and long term, and more specifically, in the palliative care context, is lacking.

The impact of unpaid caregiving on short term labor market outcomes has been extensively studied; the findings of 35 papers are summarized in a systematic review [10]. While this work is not specific to a particular patient population, nor does it consider long term outcomes, some of the findings from this review may be generalizable to the palliative context. The systematic review had four principal findings: caregivers as a group were equally as likely as non-caregivers to be in the labor force; caregivers who devoted intense amounts of time were less likely to be in the labor force; intensive caregivers who remained active in the labor market tended to reduce their hours of work; and, a paucity of work considering the relationship between caregiving and wages exists. Research conducted since the systematic review have aligned with these results summarized in Lilly, 2010 [11]. The observation that intensive caregivers are less likely to be working is particularly relevant to the palliative environment, as the home site for palliative care is characterized by enormous caregiving demands, and substantial physical and emotional involvement [2,5]. Therefore, important labor force implications of unpaid caregiving in the palliative context may be paramount.

A small number of researchers have obtained descriptive and qualitative data about caregivers' participation in the labor force in the palliative context, although studying LFP was not the primary purpose [6-9,12]. These studies reported missed time from work [6-8], lost income, and changes in labor force status [e.g. moving from full-time to part-time employment and to cease employment] [7,8] and temporal changes in employment as they relate to the progression of illness [6]. Qualitative data have demonstrated that caregiving often interrupted labor force activities [6,9,12]. None of these studies examined an array of factors that might predict labor market consequences within this palliative care context, and moreover, the temporal characteristics of labor force participation are unidentified.

A group of studies provide an in-depth view of the predictors of labor force participation [LFP] in caregivers of non-palliative care patients, using both survey and administrative data [11,13-24]. These researchers assessed the relationship between number of caregiving hours and the probability of being in the labor force [13-15,17-24] and the intensity of LFP [11,13,18-20,22-24]. Socio demographic predictors of LFP were also examined using administrative data [11,14,16,18-23]. Gender differences were studied through the examination of the effect of the number of caregiving hours on labor force hours [11,19,20,22], total number of weekly caregiving hours [11,20,21], wage rates [14], the probability of being employed [14,15,19,20,22]; and the likelihood of being the primary caregiver [14]. The relationship between age and the probability [15] and/or intensity of LFP [15,18,23] and wage rates [16,18] was considered. Finally, the socioeconomic status as a predictor of probability and/or intensity of LFP [15,18,20,22], and education level as a predictor of probability of LFP [15,16,18,22] and wage rates [16,18] was assessed. Only one of these six studies assessing socio-demographic variables was conducted in an oncology setting [16], and none were conducted within a palliative care environment. These non-palliative studies may be limited in their relevance to the palliative care context where the number of hours devoted to care tends to be relatively high and would have less variance than those in a general, non-palliative care environment. In addition, the relationship between health services utilization and LFP of caregivers has not been studied. This gap is of critical as the intensity of health services provided by professional caregivers (e.g., physicians, nurses, personal support workers),

particularly in the home setting, may influence family caregivers' ability and availability for LFP.

The results from the empirical studies that examine LFP of caregivers in non-palliative contexts may only apply to the adult children of those receiving palliative care, as spouses are often already retired when engaged in caregiving. From our previous research and that of others, we know that approximately 50% of caregivers of palliative care patients are over 60 years of age, and that caregivers consist of twice as many females as males [25,26]; reviewed in Burns [27]. Over half of caregivers are spouses of the palliative patients, 11-25% are daughters or daughters-in-law, and approximately 30% are working full-time [25,26]; reviewed in Burns [27]. Furthermore, there is evidence to suggest that intensity of caregiving varies by age; Burns found that individuals over 60 years of age tend to be involved in intense caregiving for longer periods of time [27]. This sub-group of caregivers also tend to already be retired or, importantly, prompted into early retirement in order to care. Early retirement is a concern as it presents long term economic consequences [i.e., lost wages, reduced overall pension earnings] [28], and is especially noteworthy to the labor market at a time when there is already a large proportion of individuals are retiring from the labor force.

While unpaid family caregiving has enormous potential to reduce or restrain health service expenditures, the consideration of the short and long-term economic implications of working caregivers who exit or decrease their participation in the labor market is essential. Government policies considering methods to mitigate the influence of unpaid caregiving on labor market outcomes, particularly when clear policy goals to ensure cost-effective health care and a workforce that generates revenues to sustain publicly funded services will be most successful. Targeted policies ought to provide support that empowers and enables caregivers to remain employed while simultaneously having the opportunity to engage in some level of meaningful caregiving. In order to develop these targeted policies, we first need to understand the factors that may influence LFP of caregivers in the palliative care setting, and the characteristics of caregivers who are most at-risk of exiting the labor force and incurring undesirable downstream economic implications.

Within the palliative care context, there is a paucity of research exploring the LFP of unpaid caregivers during this intense, demanding time period. Only by obtaining a comprehensive assessment of the patterns of labor force behaviors, which entails examination of the factors that predict caregivers' LFP, would we be in an informed position to assess opportunities to improve the provision of effective and efficient palliative care. Ensuring that caregivers continue to be sustained in the labor force is economically and socially responsible. Gaining a detailed and precise appreciation of the family caregiving platform is relevant to policy makers interested in reconfiguring the health system to better address the caregiving requirements of palliative care patients and their families, but also to inform the targeting of services to those caregivers for whom interventions to support their status in the labor force may be more maintainable and effective.

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