

Transitions in Labour Force Participation over the Palliative Care Trajectory

Transition de la main-d'œuvre au cours de la trajectoire des soins palliatifs



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Abstract

Background: Home-based palliative programs rely on family caregivers, who often miss time from employment. This article identified changes in caregivers' labour force participation over the palliative trajectory.

Methods: Family caregivers ($n = 262$) were interviewed biweekly to measure transitions across four employment categories.

Results: More than half of the caregivers had one employment transition and 29% had three or more. The highest proportion of transitions occurred for caregivers who were employed part-time.

Interpretation: Understanding these transitions is critical to the development of strategies tailored to caregivers to contain labour force losses and to support caregivers during a time of high caregiving demands.

Résumé

Contexte : Les programmes de soins palliatifs à domicile comptent sur la contribution des proches aidants qui, souvent, doivent s'absenter du travail. Cet article identifie les changements dans l'activité de la main-d'œuvre au cours de la trajectoire des soins palliatifs.

Méthode : Des proches aidants ($n = 262$) ont été interviewés au deux semaines afin de mesurer les transitions dans quatre catégories d'emploi.

Résultats : Plus de la moitié des proches aidants ont connu une transition d'emploi et 29 % en ont connu trois ou plus. La plus forte proportion de transition touche les proches aidants qui occupent un emploi à temps partiel.

Interprétation : La compréhension de ces transitions est essentielle pour le développement de stratégies sur mesure pour les proches aidants afin de freiner la perte de main-d'œuvre et d'aider les proches aidants en période de grande demande pour ce type d'aide.

Introduction

With a rapidly growing aging population and an increased emphasis on ambulatory and home-based palliative care, dependence on family members to provide care will continue to grow and intensify (Quality Hospice Palliative Care Coalition of Ontario 2010). Palliative care aims to improve quality of life and reduce pain and suffering for patients with a life-threatening illness and their families (Hall et al. 2011). Although palliative care recipients receive multidisciplinary care from publicly and privately financed services (Carstairs 2000), this care context relies greatly on family members to provide the majority of the day-to-day care (Munck et al. 2008; Rabow et al. 2004; Thomas et al. 2002; Wolff et al. 2007). Many family caregivers of palliative care patients miss time from work or remove themselves entirely from the labour market (Brazil et al. 2003; Covinsky et al. 1994; Eldh and Carlsson 2011; Grunfeld et al. 2004; Stommel et al. 1993; Wolff et al. 2007) to meet high caregiving demands, which has economic consequences for the family, the labour force and the society at large.

The temporal fluctuations in labour force participation (LFP) in the palliative care context have not been assessed extensively among caregivers in Canada. LFP refers to an attachment to labour market work compared to no engagement. The LFP transitions considered herein may take on one of two forms: first, adjustments in the intensity of labour market engagement, which reflect shifts between full- and part-time employment, and second, decisions to entirely withdraw or remove oneself from the labour market. Each of

these employment adjustments may be temporary (e.g., when taken over a part or all of the palliative care trajectory) or permanent (e.g., when caregivers retire). Although studies have characterized some aspects of caregivers' employment while caring for a family member, these assessments were embedded within studies where the primary focus was not transitions in LFP (Addington-Hall et al. 1992; Covinsky et al. 1994; Cui et al. 2014; Grunfeld et al. 2004; Rossi et al. 2007; Rowland et al. 2017). These studies measured time missed from employment rather than transitions (Addington-Hall et al. 1992; Covinsky et al. 1994; Grunfeld et al. 2004; Rossi et al. 2007), going on leave or being unemployed at one or two time points (Covinsky et al. 1994; Grunfeld et al. 2004; Rossi et al. 2007) and employment status at the start of caregiving without consideration of subsequent transitions (Rowland et al. 2017). Furthermore, these studies did not assess whether caregivers moved back to full- or part-time employment after being unemployed or on leave. One study conducted multiple assessments with caregivers over the palliative care trajectory; however, their focus was on productivity while at work and hours missed from employment; the study did not measure LFP transitions (Mazanec et al. 2011). While the effects of caregiving on LFP have been characterized outside of the palliative care context (Alpass et al. 2017; Berecki-Gisolf et al. 2008; Bittman et al. 2007; Carmichael and Charles 2003; Carmichael et al. 2008; Carr et al. 2018; Covinsky et al. 2001; de Moor et al. 2017; Gonzales et al. 2017; Heitmueller 2007; Jacobs et al. 2017; Kotsadam 2012; Lilly et al. 2010; Longacre et al. 2016; Nguyen and Connelly 2014; Pavalko and Henderson 2006; Schneider et al. 2013; Spiess and Schneider 2003; Van Houtven et al. 2013; Wakabayashi and Donato 2005), they do not assess all possible transitions nor do they evaluate movement between employment categories. Furthermore, application to the palliative setting may be limited, as this context is unique and fraught with intense caregiving needs and psychological stress during the final days with a family member. Further empirical work into the concept of LFP in the palliative context is necessary, as the trajectory is typically shorter and more immediate than general caregiving contexts.

Accordingly, the main purpose of this study was to estimate and describe LFP transitions of unpaid caregivers across the palliative care trajectory. Tracking the transitions that occur is very important because caregiving demands can change frequently and dramatically as a patient's status stabilizes or worsens with approaching death. A comprehensive assessment of the scale, frequency and form of labour force adjustments will inform policy responses that simultaneously advance labour, social and health policies such as improving the provision of effective care while at the same time enabling caregivers to remain in the labour force.

Methods

This study was a prospective, longitudinal cohort study that assessed caregiver LFP from admission to death for two palliative care programs in Ontario, Canada: (1) Toronto's Temmy Latner Centre for Palliative Care and (2) Niagara West Palliative Care Team.

These programs provide community- and team-based multidisciplinary palliative care, including symptom and case management, and practical/emotional support to individuals at home 24 hours per day, seven days per week. Care components include home care (medicine, nursing, personal support), outpatient clinics, hospice care and coordinated acute and tertiary palliative care. These programs offer care in ethnically diverse regions of the province and have been in existence for several years; therefore, these programs reflect current practices in home-based palliative care in Ontario.

The potential participants were: (1) primary caregivers of patients admitted to one of the two palliative care programs within the past seven days; (2) fluent in English; and (3) ≥ 18 years of age. At each palliative care program, the records clerk identified all the admissions that met the eligibility criteria. Then the research officer telephoned the eligible caregivers to screen them for inclusion and to inquire about their interest in the study. The research officer then explained the study to all the interested participants and mailed a written consent form to those who indicated that they would participate.

Data were obtained from telephonic interviews with the participants and from the palliative care program databases. The study participants were interviewed every two weeks from admission into the palliative care program until the death of the care recipient. A biweekly data-collection period was selected because the interval is short enough to minimize recall bias (Severens et al. 2000), but not so short that it overburdens the caregivers.

The caregiver LFP variables were measured using a demographic questionnaire that we developed (Guerriere et al. 2008, 2010, 2015) and adapted for this study. Respondents were asked if they were employed, and if so, whether any changes had occurred and the number of hours worked over the prior two weeks. In the first interview, the demographic questionnaire was applied, and respondents were also asked if they had made changes (as described in the previous sentence) prior to their family member entering the palliative care program. Caregivers were classified under four employment categories: Full-Time (including self-employed individuals working >30 hours per week); Part-Time (including self-employed individuals working <30 hours per week) based on the Statistics Canada's Labour Force Survey or LFS (https://www.ccsd.ca/resources/ProgressChildrenYouth/pdf/pccy_notes.pdf); On-Leave; and Not-Employed (including retirees and students).

Patient age and gender were obtained from the palliative care program databases at each of the two data collection sites. Caregiver age, gender, marital status, education and co-residence status were obtained from participant interviews using our demographic questionnaire. This demographic questionnaire is part of the Ambulatory and Home Care Record, a costing tool that assesses health and social care utilization, out-of-pocket costs and caregiving time, that we developed and have used extensively in our past work (Cai et al. 2017; Chai et al. 2013; Guerriere et al. 2008, 2015, 2016; Masucci et al. 2013) and the psychometrics have been evaluated (Guerriere et al. 2006). All data obtained in this study were entered into Excel and analyzed using SAS (SAS version 9.0, SAS Institute Inc., Cary, North Carolina,

US). An SQL server database housed the data behind enterprise class Cisco Firewalls to protect against unauthorized access.

Employment status across the palliative care trajectory was operationalized using the employment state transitions between interviews (changes per two weeks) and by the amount of time spent in each employment state over the trajectory. For the latter, proportions of time spent in each state were estimated for the entire sample. Using the four unique employment categories, 16 unique transitions between two time periods over the palliative trajectory were captured, four of which represent no change in employment categories. We quantified these employment transitions across the palliative trajectory in two ways. First, among caregivers with two or more interviews, we estimated a transition probability for each of the 16 potential unique transitions for each interview period (Time 2) relative to the preceding period (Time 1). Second, we estimated the cumulative proportion of time spent in each employment category across the palliative trajectory relative to the one reported at the baseline for all caregivers in aggregate.

Statistical significance was tested to assess for differences in transitional probabilities between spouses and adult-child caregivers using the Chi-square test.

Results

During the 26-month participant recruitment period (February 1, 2014, to April 5, 2016), 1,456 caregivers were identified as being potentially eligible for the study. Of these, 964 (66%) were contacted by the research officer, and the remainder were unreachable by telephone ($n = 492$). Consent to participate was given by 273 (28% of 964); 634 (65.7%) potential participants declined; and 57 (5.9%) care receivers died before the research officer could contact the potential caregiver participant. Of the 273 consenting participants, 11 were excluded because employment data were missing. Our results are therefore based on a sample of 262 caregiver–patient dyads, yielding a total of 1,962 interviews, consisting of 27,632 patient days. While this period is right-skewed and varies from days to over 6.4 months for the upper 25%, the length of the follow-up (study entry until death) was a median of 2.6 months and the IQR was 81 days (35–197). At times, we recruited patients close to the time of entry into the palliative care program (within two weeks) and followed them until close to their death.

Tables 1 and 2 describe the samples of patients and caregivers, respectively. The sample of patients (care recipients) comprised an almost equal number of males and females. Almost 70% of the patients were 71 years or older. Most lived with at least one other person, and the majority were married.

The caregivers mainly comprised women (around 70%). More than half of the caregivers were between 51 and 70 years of age. The majority were married, and close to 75% had obtained post-secondary school education. An almost equal number of caregivers were the spouse or the adult-child of the patient. On average, caregivers dedicated six hours per day to caregiving activities.

TABLE 1. Care recipient characteristics

Variable N	Value	Total cohort N = 262
Age (yrs.)	Mean $\pm$ SD	76.13 $\pm$ 14.38
	Median (IQR)	79 (67–87)
	≤ 40	5 (1.9%)
	41–50	8 (3.1%)
	51–60	29 (11.1%)
	61–70	42 (16.0%)
	71+	178 (67.9%)
Gender	Male	133 (50.8%)
	Female	129 (49.2%)
Marital status	Married	169 (64.5%)
	Divorced/Widowed	82 (31.3%)
	Never married	11 (4.2%)
Education	High school or less	197 (75.2%)
	Any university or vocational course	65 (24.8%)
Living arrangement	Lives alone	30 (11.5%)
	Lives with others	232 (88.5%)
Number of days observed in study	Mean $\pm$ SD	162.39 $\pm$ 194.95
	Median (IQR)	81 (35–197)
Days from death at baseline	Mean $\pm$ SD	137.06 $\pm$ 177.99
	Median (IQR)	64 (21–168)

SD: Standard Deviation, IQR: Interquartile Range

Overall, we observed many transitions among the LFP categories across the palliative care trajectory. Among these transitions, 57% of the caregivers had one transition, 14% had two transitions and 29% had three or more transitions. Figure 1 presents the average percentage of caregivers who transitioned between employment categories every two weeks. These changes occurred both while moving in and moving out of three of the categories (Full-Time [FT], Part-Time [PT] and On-Leave; Figure 1). The percentage reported for each employment category represents the proportion of caregivers who reported remaining in that employment category without making an employment transition at each interview over the whole palliative care trajectory (Figure 1 legend).

The highest proportion of two-week transitions occurred for caregivers who were PT employed. On average, 10% of caregivers in the PT employed category transitioned to FT employment every two weeks. Equal percentages transitioned from PT to On-Leave (1.4%) and from PT to Not-Employed (1.4%).

The second highest transition average was observed within the On-Leave employment category. In this category, 6.8% moved to PT and 5.1% transitioned into the Not-Employed category, every two weeks over the trajectory. No movement was observed from On-Leave to FT employment.

TABLE 2. Primary caregiver characteristics at first interview

Variable	Value	Total N = 262
Age (yrs.)	Mean $\pm$ SD	59.15 $\pm$ 13.08
	Median (IQR)	59 (52–68)
	≤ 40	21 (8.0%)
	41–50	37 (14.1%)
	51–60	91 (34.7%)
	61–70	67 (25.6%)
	71+	46 (17.6%)
Gender	Male	79 (30.2%)
	Female	183 (69.8%)
Marital status	Married	189 (72.1%)
	Divorced/Widowed	27 (10.3%)
	Never married	46 (17.6%)
Education	High school or less	67 (25.6%)
	Any university or vocational course	195 (74.4%)
Relationship to care recipient	Spouse	113 (43.1%)
	Child	129 (48.1%)
	Other	20 (7.6%)
Employment status*	Not-Employed	140 (53.4%)
	Part-Time	32 (12.21%)
	Full-Time	62 (23.6%)
	On-Leave	28 (10.7%)
Caregiver's time (number of hours per day)	Mean $\pm$ SD	6.29 $\pm$ 3.62
	Median (IQR)	6 (4–9)

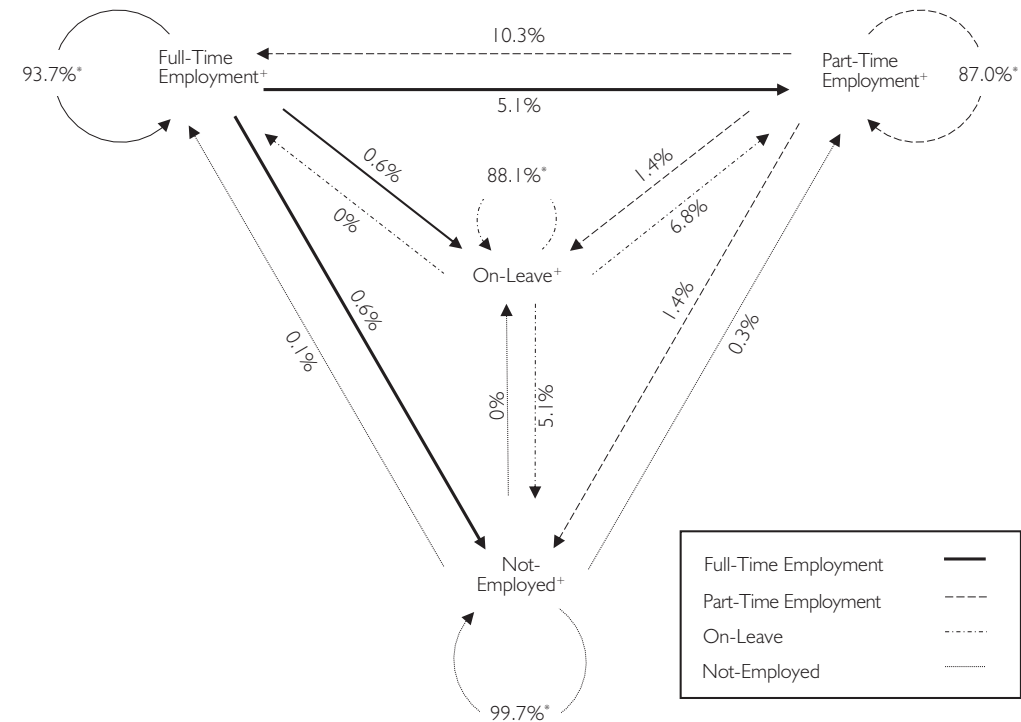
SD: Standard Deviation, IQR: Interquartile Range

Note: *At baseline

Transitions also occurred in the FT category, however, to a lesser extent than in the PT and On-Leave categories. Although the overwhelming majority (93.7%) of caregivers who were employed FT stayed in this employment category every two weeks over the trajectory, there was some movement in both directions. The highest average transition for those in the FT category was movement to PT employment (5.1%). Finally, the least amount of transitions, and thereby the largest amount of inertia, occurred in the Not-Employed category. On average, 99.7% of caregivers remained in this category every two weeks.

Overall, 93.7% of caregivers employed FT stayed FT, and this was true for both spouses (92.8%) and adult-child caregivers (94.1%; $p = 0.61$). Differences were observed for PT caregivers, with a higher proportion of transitions among adult-child caregivers (90.9%) compared to spousal caregivers (83.1%) who stayed as PT ($p = 0.21$) and the proportion of adult-child caregivers transitioning from PT to FT was also insignificant ($p = 0.14$). Just over half (51%) of all interviewees were spouses and 43% were adult-child caregivers.

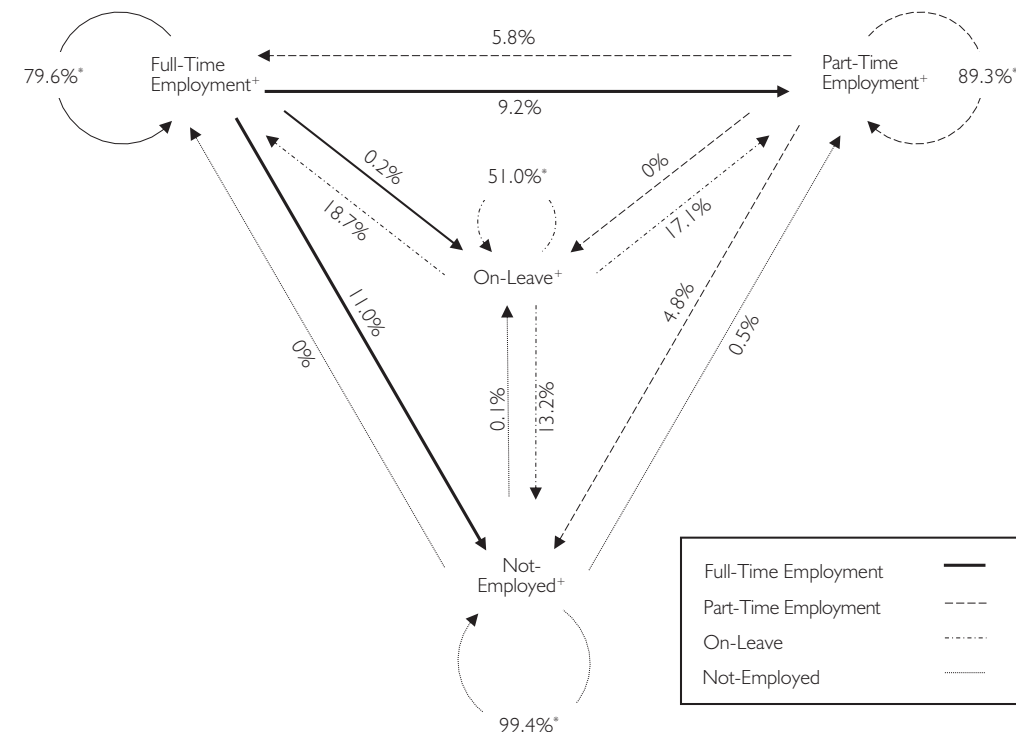
FIGURE 1. Changes in LFP over study trajectory (two-week transitions from baseline to end of follow-up; $n = 1,700$ interviews)



* Stayed in category and did not transition
+ Employment category at baseline

Figure 2 presents the cumulative proportion of time spent by a caregiver in each of the four employment categories over the two-week observation periods (i.e., from admission into the palliative program until death) relative to baseline employment. These data reflect calculations of the average transition in employment, every two weeks, over the palliative trajectory. Caregivers who were On-Leave at the start of the observation period spent the least amount of time in this category, compared to the other employment categories. These individuals spent half of their time staying On-Leave (51.0%), 35.8% of their time being employed either FT or PT and 13.2% of their time in the Not-Employed category over the course of the palliative care trajectory. Those caregivers who started in FT employment spent 11.0% of their time being Not-Employed and 9.2% of their time in PT employment. In contrast, all of the caregivers who were Not-Employed at the baseline spent almost all of their time (99.4%) in this initial state throughout the trajectory.

Figure 3 presents the transitions in employment categories that occurred prior to admission to palliative care, which is also consistent with their entry into the study. The largest percentage of change was observed for caregivers employed FT, where 50% of caregivers who were FT in the past had subsequently made an employment change prior to entering the study; almost equal percentages moved into PT (14.5%), On-Leave (18.6%) and Not-Employed (16.9%). While 50% of those who were FT did not make a transition prior to

FIGURE 2. Cumulative proportion of time spent in each of the four employment categories relative to baseline employment

* Stayed in category and did not transition

+ Employment category at baseline

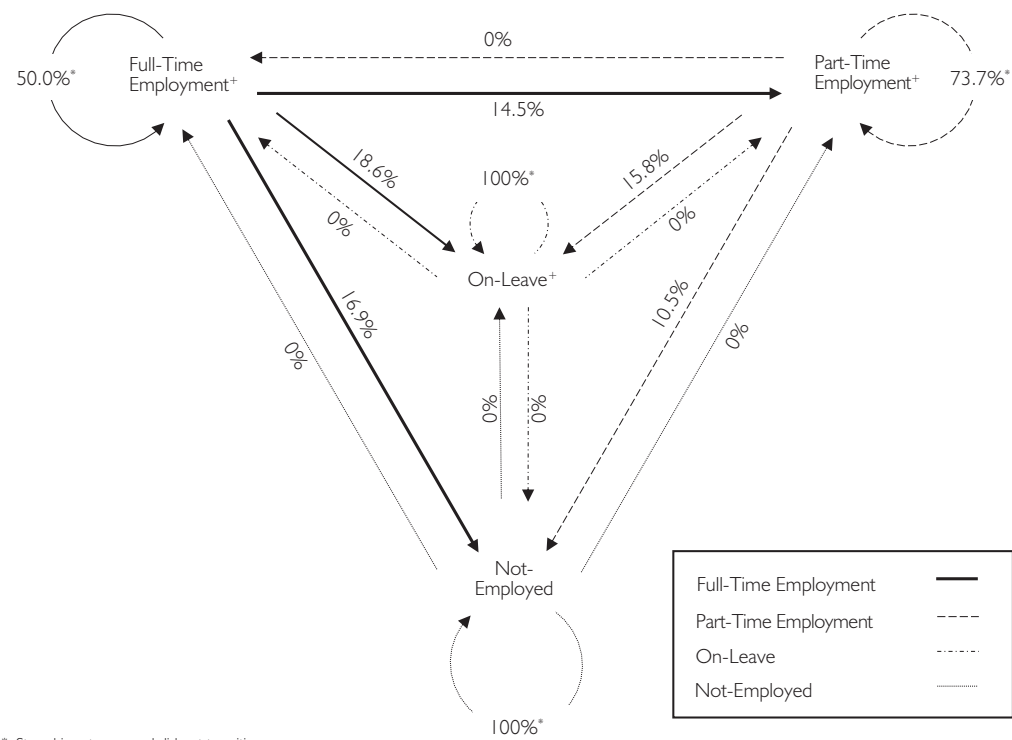
study entry, more inertia was observed for PT employed caregivers, where 74% did not transition into another employment category prior to the baseline. Of those who did transition out of PT employment, 15.8% went On-Leave and 10.5% became Not-Employed. No change in employment status occurred for caregivers who were either On-Leave or Not-Employed prior to entering the study.

While Figure 1 shows that little biweekly movement occurred into the On-Leave category during the observation period, Figure 3 demonstrates that 18.6% of FT employed caregivers and 15.8% of PT employed caregivers moved to the On-Leave category prior to the baseline.

Discussion

This prospective, longitudinal study examined transitions in a caregiver's employment status over the course of a palliative care episode and makes two main contributions. First, changes over time in the state of employment and the effect of family caregiving in palliative care on both the ability to work and the intensity of LFP (FT/PT) can be assessed (Hyslop 1999). Second, characterization of the transitions that occur permits estimation of longer term effects on employment categories that, in turn, incorporate the effects of employment interruptions on those states. While the aim of palliative care has evolved over time and now often

FIGURE 3. Changes in LFP prior to study entry (n = 262 caregivers)



* Stayed in category and did not transition

includes early intervention, it is crucial to understand the associated implications for caregivers and the impacts on their employment transitions after adjustment for other covariates.

In our study, there were transitions between employment categories as well as between hours of work, from more hours to fewer or no hours of work. As a caregiver becomes more comfortable with the palliative care environment, and as patients become clinically stable, caregivers might feel able to return to higher levels of employment. On the contrary, during intense caregiving demands, caregivers might reduce their hours of work or resign.

While it would be useful to compare our findings concerning caregiver employment transitions to other studies, this is challenging as most other studies obtained only a one-time assessment of LFP without consideration of specific changes in either employment or hours of work, and most were not in the palliative setting. With these differences in mind, we briefly discuss previous research herein to contextualize and highlight our results.

In our study, we observed that on average, 5.1% of FT caregivers transitioned to PT employment over each two-week period (Figure 1). To our knowledge, no previous study in palliative care has assessed this particular transition. In the non-palliative care context, de Moor et al. (2017) found that 2.5% of caregivers of cancer survivors transitioned from FT to PT (de Moor et al. 2017). This discrepancy in findings may be explained by the difference in the period of caregiving. Caregivers of palliative patients may be more willing to move into

part-time work, as the transition is temporary, in contrast to that for caregivers with long-term responsibilities.

In our study, transitions into the Not-Employed category were observed both during the observation period (Figure 1) and prior to the patients entering palliative care (Figure 3). Three end-of-life care studies found that the impact of caregiving on labour market attachment was much lower than that in our study. According to the three studies, only 2% of caregivers quit their job due to caregiving (Grunfeld et al. 2004), 11% quit or took time off work (Covinsky et al. 1994) and 8% resigned (Rossi et al. 2007). This contrast to our findings may be because of the transitions over time and the movement in and out of employment categories that we observed and that were not assessed in the other three studies.

In our study, we observed movement into On-Leave for caregivers in both the FT and PT categories (Figure 1). In the literature, 8–13% of caregivers reported going on-leave while caregiving for individuals with life-threatening illness (Covinsky et al. 1994; Cui et al. 2014) and in the non-palliative context (de Moor et al. 2017). Although these findings were higher than those in our study, it is important to note that in these studies, transitions were not captured at regular intervals and transitions going in both directions between not-employed and employment were not measured.

One important public and private policy goal is to foster an environment in which caregivers, including palliative caregivers, are able to either maintain their attachment to the labour force during episodes of caregiving or return to work (and/or enhance their intensity of LFP) once their episode of caregiving has concluded (Employer Panel for Caregivers 2015). Both public service agencies and private businesses have roles to play to advance this goal. First, employers can introduce flexible workplace attachment procedures that would be beneficial for all parties. Identifying which employees are caregivers and understanding the factors that influence employment transition among them is essential for planning. This is especially pertinent in the context of palliative care, as caregiving tends to occur over a relatively short period of time, compared to chronic, long-term caregiving contexts. During that critical window, support to employees in terms of workplace and leave flexibility have the potential to be beneficial to both businesses and employees. Second, by identifying how the provision of health and social care services impact caregivers' employment transitions, opportunities to simultaneously advance social and health policy as well as labour policy exist. Indeed, the judicious targeting of social and healthcare services, such as respite care, may assist palliative caregivers in their maintenance of employment. The provision of a broad range of business and public service supports may allow caregivers to move into PT employment so that they may balance their work responsibilities and their caregiving demands. This highlights the potential for important public–private partnerships in the caregiving arena rather than merely a singular public or private sector solution.

As family caregivers are fundamental to the delivery of effective home-based palliative care, it is important to ensure that they are supported. Previous research in oncology and

palliative care have pointed to the fact that family caregivers are still an underserved population (Zavagli et al. 2019). Developing and implementing policies and procedures that help to alleviate the burden for family caregivers is crucial to the delivery of compassionate palliative care. Employers who support transitions during the palliative trajectory not only enhance the well-being of caregivers but also allow palliative patients to receive effective, compassionate care from their loved ones.

Developing better models of palliative care that recognize the needs of family caregivers is an important focus for governments and healthcare institutions. Although employment insurance for compassionate care benefits exist, further attention to the role of employers is essential to support employed caregivers. Incorporating employment supports for family caregivers into home palliative care programs will allow for a more systematic and comprehensive approach to substantiate the critical role played by family caregivers.

Effective (multi-way) communication between health and social care providers and family caregivers is well recognized in the literature to advance a range of goals (Seow and Bainbridge 2018). Such discourse may address the well-being of the caregiver, including actions and supports to help them sustain employment. Ensuring that health and social care providers consider the employment status of the primary family caregiver when assessing and planning the formal care needs of palliative patients will contribute to the maintenance of employment. In addition to communicating about the patients' care, healthcare professionals can include discussion on caregivers' employment obligations and needs when planning formal care delivery. Directives are needed specifically for family caregivers in the palliative care realm. Programs such as short-term paid leave allow caregivers to provide home-based care to their ailing family member, with the assurance that they can return to the same level of employment after they fulfill their responsibilities. Furthermore, the reassurance that employees can leave to provide care without compromising their employment position and stability acts as an incentive for them to fulfill their responsibilities and return to work. These actions are likely to reduce substantially the number of caregivers who retire early due to caregiving responsibilities (Jacobs et al. 2017).

Limitations

There are three main limitations to this study. First, the data collected through interviews relied on self-reports by the participants, which introduced the possibilities of social desirability bias and non-response bias (Norman and Streiner 1986; Zarit et al. 1980). However, all the interview data were kept confidential, and we found that telephonic interviews minimized the chance of missing data, thereby reducing the possibility of non-response bias. The second limitation lay in the potential lack of generalizability of the findings. The participants were drawn from two palliative care programs, and therefore, the findings may not necessarily apply to patients receiving services outside of these programs. However, the populations served are quite diverse in terms of their clinical, demographic and ethnic backgrounds,

which may help to improve the generalizability of the findings. The third limitation was the potential for selection bias. But this bias was likely negligible given the similarity between the caregivers in the study and both the broader population of all caregivers in Canada based on gender, age and marital status (Government of Canada 2004) and the caregivers in other studies based on age, gender and relationship to the patients (Holley and Mast 2009; Macchi et al. 2020; Pinto et al. 2018).

The transitions that occurred between the various categories of LFP identified in our study are quite noteworthy. Our study shows that there are significant opportunities open to healthcare professionals, employers and public policy makers to support employed caregivers balance their twin roles in employment and at home. As the number of working family caregivers increases and their caregiving trajectories become longer, employers will need to adapt and accommodate their needs and work in partnership with health and social care agencies. Our study was designed to inform strategies that evaluate and enhance the delivery of home-based palliative care services, which may lead to the containment of labour force losses.

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