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The Importance and Challenges of Caregiving in an Aging Society

Diane-Gabrielle Tremblay and Sarah Nogues¹

Abstract

Purpose – The article presents the results of research on working time arrangements available and support offered to caregivers by employers and community organizations.

Design/methodology/approach – Both a quantitative and qualitative approach has been employed.

Findings – There are limited working time arrangements offered to caregivers, but community support that could help caregivers is not well known or used by them.

Research limitations/implications – The research on community organizations highlights the fact that these should try to make their support services better known. And a ‘right to request’ flexible working arrangements could also be useful.

Originality/value – The paper focuses on the problems of employed caregivers, which are found in most aging societies nowadays, including the EU.

Paper type – Qualitative and analytical paper.

Keywords – *Caregiving, Aging, Caregivers, Carers, Women’s work, Domestic work, Working time arrangements, Flexible work, Right to Request.*

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1. Introduction

Although many people find it both important and satisfying to care for a loved one going through a loss of autonomy, the role of caregiver creates a number of tensions and, above all, for many women, difficulties in staying employed. In this context, employers and community organizations can be an important source of support for caregivers, but these resources appear to be little known. As we were concerned with the issue of caregiving in a context of aging societies, as well as with the issue of work-life reconciliation in general²³, we looked into the situation of caregivers in particular and did some research on the support that can be offered by businesses and community organisations. Three major findings emerged from our research: 1) companies claim they offer measures but are not aware of the special needs of caregivers, in relation to other work-family needs (for example, children) and they often consider they are doing these people a favour in supporting them, without having real support strategies for caregivers; 2) community-based organizations could help caregivers reconciling work with caring for a relative; 3) we found that community services are not well known to caregivers, and perhaps some are reluctant to use them, or they do not always correspond well to needs. Let us start by presenting a picture of the situation of caregiving, to understand its importance, and then look at the measures that can be offered by business-organizations, before moving on to the option of communities' support.

2. Aging and Increasing Caregiving

In Canada, as in many other industrialized nations, demographic changes are significant and an aging population is one of the major elements that accompany it. For example, in Canada in 2015, the number of people aged 65 and over exceeded the number of children aged 0 to 14 in the population for the first time⁴. Aging is accompanied by an increased risk of disease and the number of people dependent on others⁵. Often, given the limited amount of

² D.G. Tremblay, *Conciliation emploi-famille et temps sociaux*, 4th ed., Presses de l'Université du Québec, Québec, QC, 2019.

³ D.G. Tremblay, *Articuler emploi et famille – Le rôle du soutien organisationnel au cœur de trois professions (infirmières, travailleuses sociales et policiers)*, Presses de l'Université du Québec, Québec, QC, 2012.

⁴ Statistics Canada, *Annual Demographic Estimates – Canada, Provinces and Territories, 2015*, <https://www150.statcan.gc.ca/n1/pub/91-215-x/2015000/aftertoc-aprestdm1-eng.htm> (accessed September 19, 2019)

⁵ Y. Decady, L. Greenberg, *Ninety Years of Change in Life Expectancy, Health at a Glance*, Statistics Canada, 2014, <https://www150.statcan.gc.ca/n1/pub/82-624-x/2014001/article/14009-eng.htm> (accessed September 19, 2019)

public resources in many countries, it is the family, and often women in fact, that are the main resource for the care of elderly people who are either losing their autonomy, sick or dependent⁶. It is these family members, or the wider social network including neighbours and friends, who are referred to as close caregivers.

Since the majority of these people is employed⁷, they often experience tensions associated with the difficult articulation between their care responsibilities and their professional responsibilities, which is costly for individuals and society alike⁸⁹.

Our research has shown that women in employment who are also close caregivers start by reducing their hours of work, and then, if they still can't reconcile work and care responsibilities, they end up quitting their jobs. Our detailed interviews with caregivers captured the case of women retiring earlier than expected because of care duties, resulting in financial difficulties especially when the person cared for was the spouse¹⁰. Given the continuing aging of populations, the shortage of labour in many sectors, including women's sectors (health, education, hospitality, catering, etc.), as well as women's desire to remain employed, it is important to find solutions, which is why we have been interested in the support that the community sector can offer.

Indeed, while the support of supervisors and colleagues is important in the workplace, companies are not really aware of the difficulties associated with caregiving, they have little or no specific policies or practices in this regard and believe that the general measures offered in the company are sufficient for work-life reconciliation in general, as for caregivers. However, the necessary support is not always provided, and in general, employers are not very aware of the issue and challenges related to caregiving for elderly or sick parents (Figure

⁶ J. Lamontagne, M. Beaulieu, *Accompagner son conjoint âgé en soins palliatifs à domicile – Les éléments influençant l'expérience des proches aidants*, in *Nouvelles pratiques sociales*, 2006, vol. 19, n.2, 142-156.

⁷ M. Sinha, *Portrait of Caregivers, 2012, Spotlight on Canadians – Results from the General Social Survey*, Statistics Canada, 2013, <https://www150.statcan.gc.ca/n1/pub/89-652-x/89-652-x2013001-eng.htm> (accessed September 19, 2019)

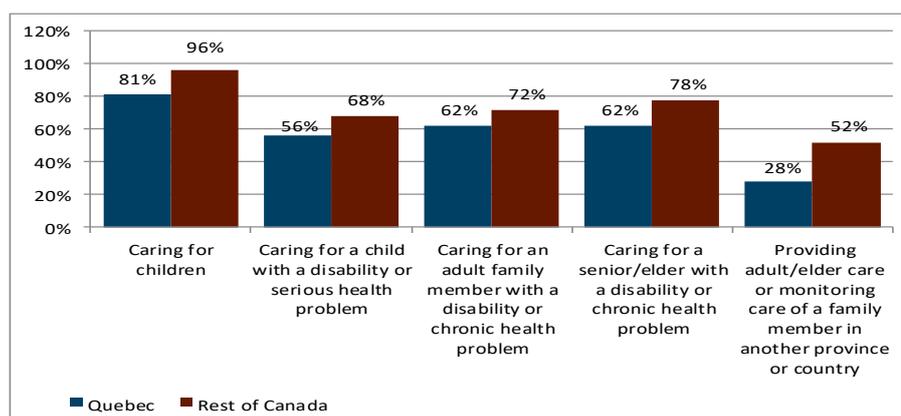
⁸ L. Duxbury, C. Higgins, B. Schroeder, *Balancing Paid Work and Caregiving Responsibilities – A Closer Look at Family Caregivers in Canada*, Human Resources and Skill Development Canada, 2009, http://rcrpp.org/documents/51061_EN.pdf (accessed September 19, 2019)

⁹ J. Fast, D. Lero, N. Keating, J. Eales, K. Duncan, *The Economic Costs of Care to Employers – A Synthesis of Findings (research document)*, Employment and Social Development Canada, 2014a, https://www.worklifecanada.ca/cms/resources/files/678/Economic_Costs_of_Care.pdf (accessed September 19, 2019)

¹⁰ S. Nogues, *Concilier emploi et soins à un proche dépendant: Du soutien organisationnel et personnel au soutien communautaire*, 2018, Masters thesis, École des Sciences de la Gestion/School of Management, UQAM, Montreal, QC.

1), much less than they are for responsibilities related to children. Moreover, they do not make the issue of caregiving a priority as our data has shown that only half of the surveyed employers indicate it is a priority, while the other half consider that they are doing employees a favour in trying to meet their expectations¹¹. It is also noted that caregiving is less familiar to firms than issues of parenting or care for young children (Figure 1). Also, in any case, the workplace does not actually offer adequate or sufficient measures, according to our interviews with family caregivers¹²¹³¹⁴, even though companies claim to have put in place a certain number of measures (Figure 2). Given this situation, it is important that other resources help caregivers so that they can stay in employment, should they want to do so.

Figure 1. Employers' Experiences with Employees Who Have or Are Currently Providing Various Types of Care¹⁵



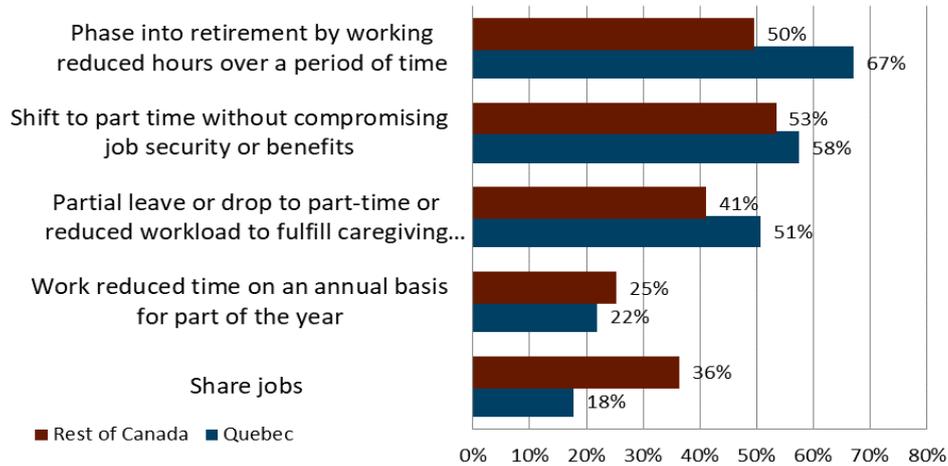
¹¹ D. Lero, N. Spinks, J. Fast, M. Hilbrecht, D.G.Tremblay, The Availability, Accessibility and Effectiveness of Workplace Supports for Canadian Caregivers – Final Report, Vanier Institute of the Family, 2012, https://www.worklifecanada.ca/cms/resources/files/703/The_Availability,_Accessibility_and_Effectiveness_of_Workplace_Supports_for_Canadian_Caregivers.pdf (accessed September 19, 2019)

¹² D.G. Tremblay, Conciliation emploi-famille et enjeux d'inclusion sur le marché du travail – Le cas des travailleuses proches aidantes, Presented at the conference *Pour une approche inclusive du travail et de la formation*, Tours, France, April, 2019a.

¹³ S. Nogues, D.G. Tremblay, La conciliation emploi-famille-soins : Analyse comparative des besoins et du soutien organisationnel, in *Nouvelle Pratiques Sociales*, 2018, vol. 30, n.1, <https://doi.org/10.7202/1051410ar>

¹⁴ S. Nogues, D.G. Tremblay, Concilier travail et soins à un proche au Canada : quel soutien des acteurs communautaires? In *Canadian Journal of Research on NPOs and Social Economy*, 2017, vol. 7, n.2, 17-39.

¹⁵ Retrieved from D. Lero et al., 2012, *op. cit.*

Figure 2. Flexibility and Reduced Work Options¹⁶

Yet, very few researchers have looked at community resources as a possible source of support for employees who are also close caregivers. We found that, despite a relatively diverse community support offer, only a minority of caregivers uses these services. The problem keeps on growing but it already concerns many Canadians, and many people in other industrialized nations.

The 2012 Canadian General Social Survey (GSS) indicated that 13 million Canadians aged 15 and over, or almost half of the population (46 per cent), had cared for a dependent relative at least once in their lifetime¹⁷. Between 2011 and 2012, 8.1 million Canadians experienced care responsibilities, i.e. for support in day-to-day tasks (household chores, transportation), for physical and medical care (bathing, accompanying to the toilets, administering medicines) or for administrative assistance, including property management^{18,19}. According to the GSS, caregivers spend on average three hours per week caring for a loved one, but this varies considerably depending on the type of care and gender. For example, it would be 10 hours a week when caring for a sick child and up to 14 hours to care for a spouse. In addition, women spend

¹⁶ *Idem*

¹⁷ M. Sinha, 2013, *op.cit.*

¹⁸ K.L. Davis, D.B. Marin, R. Kane, D. Patrick, E.R. Peskind, M.A. Raskind, K.L. Pudler, The Caregiver Activity Survey (CAS) – Development and Validation of a New Measure for Caregivers of Persons with Alzheimer’s Disease, in *International Journal of Geriatric Psychology*, 1997, vol. 12, 978-988.

¹⁹ B. Van den Berg, P. Spauwen, Measurement of Informal Care – An Empirical Study into the Valid Measurement of Time Spent on Informal Caregiving, in *Health Economics*, 2006, vol. 15, 447-460.

on average more hours caring than men²⁰. In some cases, the number of hours is almost equivalent to a second full-time job. In fact, 60 per cent of caregivers, or 4.8 million Canadians,^{21,22} combine care with paid employment.

Finally, the majority of caregivers who have a job is part of what is called the 'sandwich' generation, because they also have parental responsibilities with children.²³

Given the scope of their responsibilities, caregivers unsurprisingly show higher rates of fatigue, muscle pain, and heart and chronic disease than non-caregivers^{24,25}. They also face higher levels of stress, depression and guilt²⁶. Moreover, they are prone to impoverishment, especially among women, who often reduce their working hours or leave their jobs to care full-time^{27, 28}. In 2012, this represented an estimated loss of CAD\$220.5 million for women and CAD\$116.3 million for men in Canada.²⁹

All of these challenges experienced by caregivers, who make up about 30% of the Canadian workforce³⁰, also have negative effects on businesses. Some authors³¹ estimated the cost of the turnover rate associated with caregiving for Canadian employers at CAD\$3.8 billion. Scholars also reported that in 2012 in Canada, 9.7 million workdays were lost, 256 million hours of work were reduced and 557,698 employees left the labour market to care for a loved one³²

However, employment is important for caregivers. Indeed, in addition to securing an income, which is of paramount importance, having a job allows

²⁰ M. Sinha, 2013, *op. cit.*

²¹ J. Fast et al., 2014a, *op. cit.*

²² M. Sinha, 2013, *op. cit.*

²³ D.G. Tremblay, 2019b, *op. cit.*

²⁴ L.N. Bialon, S. Coke, A Study on Caregiver Burden: Stressors, Challenges, and Possible Solutions, in *American Journal of Hospice and Palliative Medicine*, vol. 29, n.3, 210-218.

²⁵ A. M. Williams, L. Wang, P. Kitchen, Impacts of Caregiving and Sources of Support: A Comparison of End-of-life and Non-end-of-life Caregivers in Canada, in *Health and Social Care in the community*, vol. 24, n.2, 214-224.

²⁶ L. Duxbury et al., 2009, *op. cit.*

²⁷ M. B. Lilly, A. Laporte, P. Coyte, Labor Market Work and Home Care's Unpaid Caregivers: A Systematic Review of Labor, in *Milbank Quarterly*, vol. 85, n.4, 641-690.

²⁸ Lilly, Laporte and Coyte, 2007, *op.cit.*; Sinha, 2013, *op. cit.*

²⁹ Fast, 2015, *op. cit.*

³⁰ *Ibid.*

³¹ Fast, Lero, Keating, Eales and Duncan, 2014, *op. cit.*

³² J. Fast, D. Lero, R. DeMarco, H. Ferreira, J. Eales, Combining Care and Paid Work : Is it Sustainable? Research on Aging, Policies and Practice (RAPP), Edmonton, 2014b, https://rapp.ualberta.ca/wp-content/uploads/sites/49/2018/04/Combining_care_work_and_paid_work_2014-09-16.pdf (Accessed October 24, 2019)

one to experience something outside the caring activity, to be valued and to maintain contact with other people.

4. Support for Caregivers

Canadian caregivers can benefit from government financial assistance, with the Family Caregiver Tax Credit, amounting to a maximum of CAD\$6,986 in 2018³³, or compassionate care benefits that allow an employee to take six months off to accompany a loved one at the end of life, at a maximum of \$562 per week³⁴. Under certain conditions, non-end-of life caregivers are entitled to two days of paid leave, employment insurance benefits for caregivers. However, beyond that, many would need more regular support. In this regard, community actors can play an important role in helping caregivers navigate healthcare services³⁵. There is no shortage of services, but rather an underutilization of these services according to several authors, and that is also what we have observed in our research. In addition, it appears that there is some reluctance on the part of caregivers to use such services, because they often feel compelled to help their parents or relatives themselves^{36,37}. There may also be an overdose of information discouraging the search for help³⁸. Scholarship has highlighted other factors explaining this underutilisation of services³⁹, which we also found in our interviews: the heaviness or difficulty of the caring situation, the intensity of the needs of the person cared for, as well as caregivers' own personal organization capacities and proactivity in looking for help and finding adequate resources. In our research, we have tried to

³³ Government of Canada, The New Canada Caregiver Credit, 2018, <https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/about-your-tax-return/tax-return/completing-a-tax-return/deductions-credits-expenses/canada-caregiver-amount.html> (accessed September 19, 2019)

³⁴ Government of Canada, Employment Insurance Caregiving Benefits and Leave: What Caregiving Benefits Offer, 2019, <https://www.canada.ca/en/services/benefits/ei/caregiving.html> (accessed September 19, 2019)

³⁵ B. Schroeder, J. McDonald, J. Shamian, Older Workers with Caregiving Responsibilities – A Canadian Perspective on Corporate Caring, in Ageing International, 2012, vol. 37, 39-56.

³⁶ J.R. Robinson, A. Fortinsky, N. Kleppinger, N. Shugrue, M. Porter, Caregiving and Caregiver Conditions on Depressive Symptoms, Health, Work and Social Isolation, in Journal of Gerontology: Social Sciences, 2013, vol.64B, n.6, 788-798.

³⁷ S. Nogues, 2018, *op. cit.*

³⁸ B. W. Winslow, Family Caregivers' Experiences with Community Services – A qualitative Analysis, in Public Health Nursing, vol. 20, n.5, 341-348.

³⁹ R. Pepin, A. A. Williams, L. N. Anderson, S. H. Qualls, A preliminary Typology of Caregivers and Effects on Service Utilization of Caregiver Counseling. In Aging & Mental Health, vol. 17, n.4, 495-507.

determine how community actors contribute to the work-family balance of caregivers, and how they support them in their caregiving journey

5. Our Results on Community Support

We have chosen to investigate how employed caregivers benefit from community support through the lens of social support theory. Social support is found through various social ties with other individuals, groups and the wider community⁴⁰ and is broadly characterized as an exchange of emotional and instrumental resources as a response to a given need⁴¹. While emotional support typically refers to verbal exchanges and active listening, instrumental support is rather focused on concrete assistance⁴². Regarding the methodology of our research, we opted for an exploratory design involving in-depth interviews with caregivers (23) and others with representatives of community organizations (12).

We have seen that while community services can be a resource to facilitate caregiving work, they are not always well known. Yet community services can provide respite for caregivers. In addition, emotional support through listening and counselling can reduce tension and help caregivers stay in employment, especially when there is no other support, in the workplace or elsewhere. This community support can be particularly important because it can keep employed caregivers stay in employment and not to have to reduce their hours, as we have seen in our interviews with women offering more than 20 hours of care per week. Furthermore, our results indicate that the emotional support provided by the community, through one-on-one meetings or peer support groups, is mainly used at times of crisis (exhaustion or burnout) or after retirement.

We found that employed caregivers mostly use respite and household services from community organizations and are much less likely to take part in the socialising activities offered by community organizations, while the latter consider that these activities (e.g. psychosocial help, peer support groups) are very important resources for caregivers facing a myriad of challenges.

Our research allows us to conclude with three main observations: on the one hand, our results show that companies are not doing everything they should to support caregivers, at least these people feel that the measures and support are insufficient and not always adapted to their situation. As a result, as noted

⁴⁰ N. Lin, Building a Network of Social Capital, in *Connections*, 1999, vol. 11, n.1, 28-51.

⁴¹ S. G. Cohen, Gottlieb, B. H. et Underwood, L.G., Social relationships and health, in S. Cohen, L.G. Underwood, B.H.Gottlieb, B. H. (eds), *Social Support Measurement and Intervention*, Oxford University Press, New York, 2000, 3-25.

⁴² J. S. House, *Work Stress and Social Support*, Addison-Welsey, 156 p.

above, caregivers, especially women, will often reduce their hours of work and eventually end up quitting their jobs prematurely. On the other hand, the community sector is still relatively unknown to the public and caregivers, despite its importance in the Quebec and Canadian economy, and possibly as well in other countries. However, caregivers who are employed and add their caring responsibilities on top of their job, do not seem to participate in activities offered by the community sector, such as psychosocial or peer support, but rather mostly look into the services similar to those offered by the public services (household, respite), which are not always sufficient and can be costly.

6. Final Words on Workplace Accommodation and the ‘Right to Request’ Flexible Work

In the workplace, recent changes in Canada Labour Code (applicable only to Canadian companies covered by this code, and not to all Canadian companies) have granted employees the right to formally request their employer accommodations in order to attend to various life concerns. This ‘Right to request’ flexible work, which came into force on September 1, 2019 in Canada⁴³, has been in force for several years in the UK, New Zealand and Australia, as well as some States of the US. Considering the importance of flexible work options (e.g. flextime, telework, compressed workweek, time off in lieu, etc.) for caregivers^{44,45}, this right appears as an important progress in terms of employee accommodation, which is why we questioned in a previous work whether it would be particularly useful for employed caregivers⁴⁶. While our review of existent findings revealed little evidence of positive impacts of this law according to studies led in various workplaces of Anglo-Saxon countries, a slight change was still observed towards a higher propensity of employers to grant more flexible options to employees in the UK, when

⁴³ S. Todd, R. Devon, Sweeping Changes to the Canada Labor Code in Force September 1, 2019 – Federal Employers, are you prepared? August 2019, <http://www.mondaq.com/canada/x/836608/employee+rights+labour+relations/OECD+Public+Consultation+Document+And+Public+Commentary+On+The+Tax+Challenges+Of+Digitalisation> (accessed September 19, 2019)

⁴⁴ M. Zuba, U. Schneider, What Helps Informal Caregivers? The Role of Workplace Characteristics in Balancing Work and Adult-Care Responsibilities, in *Journal of Family and Economic Issues*, vol. 34, 460-469.

⁴⁵ E.K. Pavalko, K. A. Henderson, Combining Care Work and Paid Care Work: Do Workplace Policies Make a Difference? In *Research on Ageing*, 2006, vol. 28, n.1, 359-374.

⁴⁶ S. Nogues, D.G. Tremblay, Le ‘Right to request flexible work’, un instrument de politique favorable pour les employés proches aidants? In *Analyses de Politiques/ Canadian Public Policy*, 2017, vol. 43, n.4, 442-455.

considering larger datasets at the country level and over the course of several years.

Thus, the ‘Right to request’ concurs to foster a culture of accommodation and work-life balance more than it constrains employers in granting employees’ requests for flexible accommodation⁴⁷. Indeed, this right is no guarantee that employees will obtain the requested accommodation from their employer, since the latter can reject the request based on various business grounds. This implies that employees working in certain industries and types of jobs which appear harder to accommodate (e.g. a frontline employee in a manufacture or in a service firm) will have fewer chances to benefit from workplace flexibility compared to others (e.g. a white-collar employee in a bank). There has thus been concern that the Right to request, while it may concur for a change in corporate culture towards a greater consideration and respect for employees’ lives outside of work, generates further inequalities in the workforce and cannot be considered as a law that really protects workers⁴⁸. However, greater awareness of employee’s care-related needs remains an important outcome of this law, as it may invite managers and supervisors to be more understanding of, and more knowledgeable about, such situations ,which in turn is likely to positively affect caregivers’ well-being at work through supervisor support⁴⁹.

Given the growing proportion of caregivers in the workforce, more efforts should be done in the direction of accommodating employed caregivers. It seems important for employers to conduct anonymous surveys in order to determine what percentage of their workforce is providing care to a dependent adult or child with special needs, and what would these employees need the most in terms of accommodation. From there on, it would be beneficial to promote bundles of measures and practices (e.g. flextime, telework, care benefits, extended paid leaves, employee assistance program etc.) whereby employees would feel that they have a “safety net” allowing them to remain employed all the while pursuing their care duties⁵⁰. Finally, from a public health prevention and promotion point of view, workplaces constitute ideal pools to target special groups of the population for interventions. Therefore, increased collaboration between businesses and the community is strongly advocated for,

⁴⁷ See for instance: N. B. Skinner, B. Pocock, *The Persistent Challenge: Living, Working and Caring in Australia in 2014*, The Australian Work and Life Index, Centre for Work and Life, 2014, University of Meridional Australia, Adelaide.

⁴⁸ See for instance: A. Hegewisch, *Flexible Working Policies: A Comparative Review*, Research Report n.16 for the Human Rights commission, 2009, EHRC: Manchester.

⁴⁹ H. Zacher, H. Schultz, *Employees’ Eldercare Demands, Strain and Perceived Support*, *Journal of Managerial Psychology*, vol. 30, n.2, 183-198.

⁵⁰ S. Nogues, 2018, *op cit.*

in order to work towards a greater awareness of caregiving challenges, and towards more solutions for this major contemporary issue.

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