Policies and Resources Identified by Youth as Being Important to Prepare for Caregiving Responsibilities

Minakshi Raj, PhD, MPH, Sara J. Feldman, MPH, and Tammy Chang, MD, MPH, MS

Background: **Youth are increasingly upholding significant caregiving responsibilities. These caregiving responsibilities can have emotional, educational, and professional impacts on youth and young adults. And yet, policies and resources focus on adult caregivers and are limited in supporting young caregivers. The purpose of this study was to describe the different types of support that youth identify as being important to prepare to take care of an adult relative.**

Methods: **We conducted an open-ended, text-message based poll of youth ages 14 to 24 in August 2020. We conducted a content analysis to categorize and describe the different types of support respondents identified in their responses. We compared types of support identified by age-group, gender identity, and prior caregiving experience.**

Results: **Most respondents (42.2%) identified education (eg, skills training) as being an important resource. Other types of support reported included financial support (eg, assistive programs), workplace policies (eg, paid leave), mental health support, and professional support.**

Discussion: **Policy makers should extend existing policies (eg, Family and Medical Leave Act) to include and consider the circumstances of youth and young adults. Policies enabling young caregivers to actively participate in their adult relative's health care visits could be critical to preparing youth for the skills required and the physical and emotional demands associated with caregiving. Coordinated efforts between health and education systems could support youth in learning information about caregiving, medical decision making, and medical tasks. (J Am Board Fam Med 2022;35:814–820.)**

Keywords: **Adolescent, Caregivers, Clinical Decision-Making, Delivery of Health Care, Family Leave, Health Policy, Health Promotion, Surveys and Questionnaires, Workplace, Young Adult**

Introduction

Over one third of youth (age 14 to 24) provide previous or current caregiving support for tasks such as transportation, emotional support, monitoring safety, and dementia care, to an adult relative independently or with another relative and experience lasting impacts on physical and mental health outcomes, school performance, and employment.[1–9] However, the vast majority of clinical and/or community interventions focus solely on adult rather than young caregivers.[10–15]

State and national policies supporting young caregivers are even more sparse and often neglect their distinct circumstances.[16] For instance, youth working while attending school may not benefit from the Family and Medical Leave Act (FMLA) since they are likely working too few hours to meet eligibility criteria.[17–19] Young caregivers are increasingly

---

This article was externally peer reviewed.

Submitted 31 December 2021; revised 4 March 2022; accepted 8 March 2022.

From Department of Kinesiology and Community Health, University of Illinois Urbana-Champaign, Champaign, IL (MR), Department of Health Behavior and Health Education, University of Michigan School of Public Health, Ann Arbor, MI (SJF), Department of Family Medicine and Institute for Healthcare Policy and Innovation, University of Michigan Ann Arbor, MI (TC).

Funding: This work was supported by the Department of Kinesiology and Community Health at the University of Illinois Urbana-Champaign (MR), the Michigan Institute for Clinical and Health Research and the University of Michigan Department of Family Medicine (TC), and a predoctoral fellowship from the National Human Genome Research Institute (T32 HG010030) (SJF).

Conflicting interests: None.

Corresponding author: Minakshi Raj, PhD, MPH, 2007 Huff Hall, 1206 South Fourth Street, Department of Kinesiology and Community Health, Champaign, IL 61820 (E-mail: mraj@illinois.edu).

stepping into caregiving roles to accommodate gaps in needed supportive care to adult relatives as more adults are shouldering dual employment and caregiving responsibilities.[20,21] But rather than having specific resources or policies for young caregivers, there is a reliance on resources for adult caregivers presumed relevant for young caregivers.[22]

Here, we present findings on the different types of support that youth identify and express as being important for preparing care for an adult relative to facilitate development of youth-informed caregiving policies and resources.[18,23]

Methods

Participants were recruited online to MyVoice, a national open-ended text message poll of youth ages 14 to 24 years, through social media advertising to meet national benchmarks based on weight samples of the American Community Survey. Participants are sent weekly surveys on relevant health topics via text-messaging given high mobile phone access in this age-group (over 70% by age 14).[24,25] Here, we report findings from our use of the MyVoice poll to study caregiving specifically. Demographic information was collected at enrollment.[26] This study was approved by the University of Michigan Institutional Review Board and was fielded in August 2020.

Open-ended questions were developed through an iterative process with survey, mixed methods, and caregiving experts, and youth. The study included 5 questions on caregiving experiences and perspectives (eg, impact of caregiving) and was introduced with a prompt: *This week is about family caregiving (taking care of an adult relative)*.[27] This report focuses on the question: *What would help you prepare to take care of an adult relative in the future?*

We conducted a content analysis to analyze respondents' descriptions, which were submitted in a narrative format. We first read through all responses and developed a preliminary codebook of identified resources. Then, 2 investigators refined codes, independently coded all responses using Microsoft Excel, and resolved discrepancies through discussions.[28] We assessed the frequency with which respondents identified each type of support among the full sample, then among respondents with caregiving experience and by age-group; summarized demographic characteristics (age, sex, race/ethnicity, socioeconomic status, region of the country); and conducted χ^2 tests to evaluate the relationship between age-group (14 to 18, 19 to 24) and identified supports. Caregiving experience was measured by asking whether respondents had ever taken care of an adult relative (described elsewhere) and was not explicitly defined in the survey, to solicit a range of caregiving experiences.[1]

Results

Of 1076 youth who received the question, we analyzed 905 complete responses (response rate = 84.1%). Nearly half (46.5%) self-identified as female

Table 1. Characteristics of the Study Sample (n = 905)

	Full Sample[a]
	Frequency (%)
Age, Mean (SD)	18.9 (2.7)
14 to 18	467 (51.6)
19 to 24	438 (48.4)
Gender	
Female	421 (46.5)
Male	408 (45.1)
Transgender	40 (4.4)
Nonbinary	30 (3.3)
Other	5 (0.6)
Race/Ethnicity	
White/Caucasian, NH	511 (66.1)
Black/African American, NH	77 (10.0)
Asian, NH	128 (16.6)
2+ Races, NH	52 (6.7)
Other, NH[b]	5 (0.7)
Hispanic	120 (13.4)
Highest educational attainment	
Some high school or less[c]	362 (40.0)
High school graduate	138 (15.2)
Some college/ vocational training/associate degree	286 (31.6)
Bachelor's degree or higher	117 (12.9)
Region of U.S.	
West	197 (21.8)
Midwest	302 (33.4)
South	254 (28.1)
Northeast	148 (16.4)
Qualification for free/reduced lunch	
Yes	342 (37.8)
Previous or current caregiving experience	349 (38.6)

[a] Note: n = 893 to 905 due to missing values.
[b] Includes Native Hawaiian or Other Pacific Islander, American Indian or Alaska Native.
[c] Includes currently in High School.
Abbreviations: NH, Native Hawaiian; SD, standard deviation.

and 51.6% were age 14 to 18 years. More than half of respondents (60%) had at least a high school degree (Table 1).

Respondents described several different types of resources to prepare them for caregiving responsibilities. These included: education (42.2%; eg, informational videos, skills training from professionals); financial stability (26.3%; eg, savings, public assistance programs); workplace support (6.4%; eg, working from home, leave, or flexible work hours during demanding caregiving periods); social/professional support (15.6%; eg, hired workers or relatives to assist with caregiving), time and space (9.8%; eg, a large enough home), advance care planning (9.6%; ie, early conversations with their relative about needs and preferences), and mental health support (3.8%; eg, access to treatment, respite, and opportunities to mentally prepare for caregiving). Table 2 provides illustrative quotes of the different types of support.

The majority of respondents identifying financial support were female (52.5%) and in the 19 to 24 age-group (54.6%, Figure 2). Respondents age 19 to 24 years were significantly more likely than respondents age 14 to 18 to identify workplace policies, X^2, (2, n = 905)=23.7, $P < .001$ and social/professional support, X^2, (2, n = 905)=10.6, $P = .001$. Respondents ages 14 to 18 were significantly more likely to identify education than those ages 19 to 24, X^2, (2, n = 905)=5.2, $P < .05$ (Figure 1).

Among 349 respondents with complete responses about current or prior caregiving experience who also discussed types of support (38.6%), education was the most commonly reported type of support (42.9%) followed by financial support (23.7%; Figure 2).

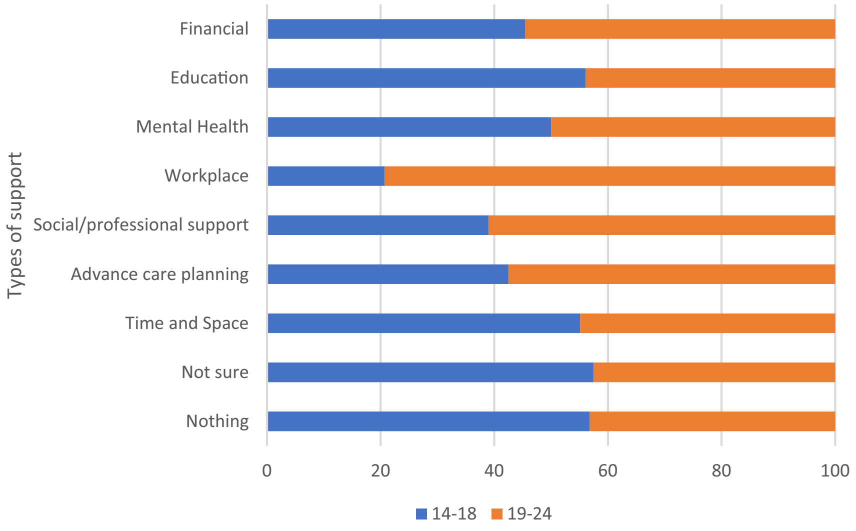
Workplace support was the most common type of support indicated by experienced caregivers in the 19 to 24 age-group (70%) followed by social/professional support (60%) and financial support

Table 2. Resources to Support Youth in Current or Future Caregiving Responsibilities Identified by Respondents Age 14-24 (n = 905)

	Frequency (%)	Representative Quotes
Education	382 (42.2)	"Knowing what are some common mistakes maybe" 18, male, White or Caucasian "Guidebooks, informational videos or podcasts, medical resources available for how to correctly take care of them" 21, female, White or Caucasian
Financial support	238 (26.3)	"Financial safety net, resources, help from others" 18, female, Asian "Having a strong financial backing" 20, male, Native Hawaiian or other Pacific Islander and White
Social/ professional support	141 (15.6)	"I'd hire a caregiver for them, or look after them during my free time" 15, female, Asian "Have funds set aside so I can pause work or even hire someone to help so I can finish things I need to do" 24, nonbinary, White or Caucasian
Time and space	89 (9.8)	"Time, simply just the time to dedicate to taking care of them" 16, male, White or Caucasian "Making sure I live in an environment that's safe for them" 19, nonbinary, Black or African American
Advance care planning	87 (9.6)	"Lay out a plan in advance that way we wouldn't have to think about it in a cramped amount of time" 14, male, White or Caucasian "Knowing what kinds of issues they have and how my actions affect them/what I can do to support them" 19, male, Asian
Not sure	80 (8.8)	I'm not sure." 17, female, White or Caucasian "I'm not sure. I wouldn't know what ways to prepare." 19, female, Other (Hispanic)
Workplace	58 (6.4)	"Stability, having a job that would accommodate the time and energy needed to take care of the person while also still working" 17, female, Asian "I would need some kind of training, or even a class on how to be a proper caregiver. I would also need the ability to take time off of work if needed" 24, transgender, Black or African American and White or Caucasian
Nothing	44 (4.9)	"I don't think anything could" 18, transgender, White or Caucasian "Nothing prepares you for it. You learn as you go. Maybe working at a retirement home would help some. As well as therapy." 19, female, White or Caucasian
Mental health support	34 (3.8)	"I wish I would've known the emotional bank it takes to put energy into both yourself and another human being. I wasn't prepared to drain myself for her but that's exactly what I did. If there were a way I could prepare myself for the imbalance I would've taken it." 18, female, Black or African American "Having a plan for respite" 24, female, White or Caucasian

Note: Respondents may have indicated multiple types of resources.

Figure 1. Types of support identified by youth, by age (n = 905).



(58%). Among experienced caregivers in the 14 to 18 age-group, the most common response was that nothing can prepare one for caregiving (60%) followed by mental health support (57%) and education (53%; Figure 3).

Discussion

In this study, youth identified several types of support to prepare them for caregiving: education, financial support, workplace policies, social/professional support, mental health support, advance care planning, and time and space. Approximately 7% of respondents described a lack of clarity around what can help them prepare to be a caregiver; some also acknowledged—or resigned—that nothing can prepare one for caregiving. Respondents evenly endorsed the types of resources identified regardless of age, though respondents identifying workplace policies as a resource were predominantly age 19 to 24, perhaps reflective of their experiences in the transition from education to work environments, while respondents in the 14 to 18 age-group were focused on education and mental health.

Moving forward on types of support identified by respondents requires coordinated efforts between policy makers, clinicians, and educators. Lack of clarity around what can help prepare for caregiving was mostly due to a lack of exposure or perceived obstacles to caregiving, and may represent a need for

Figure 2. Types of support reported by youth with caregiving experience (n = 349).

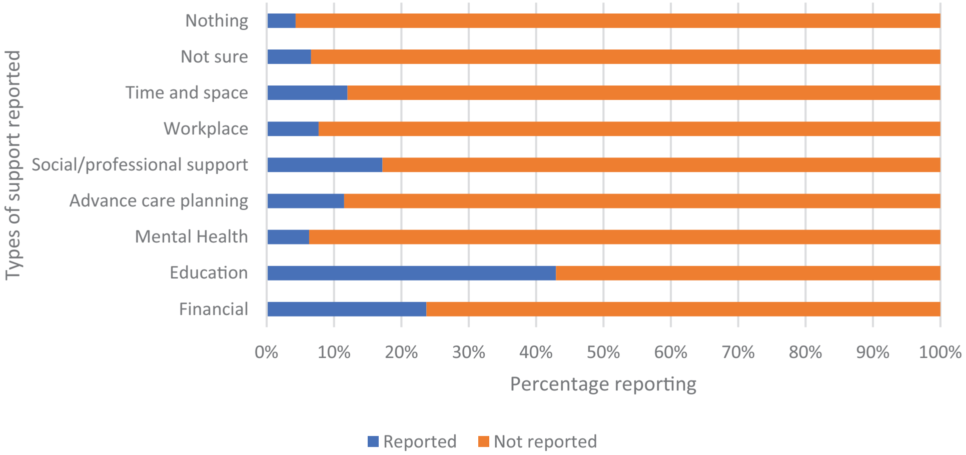
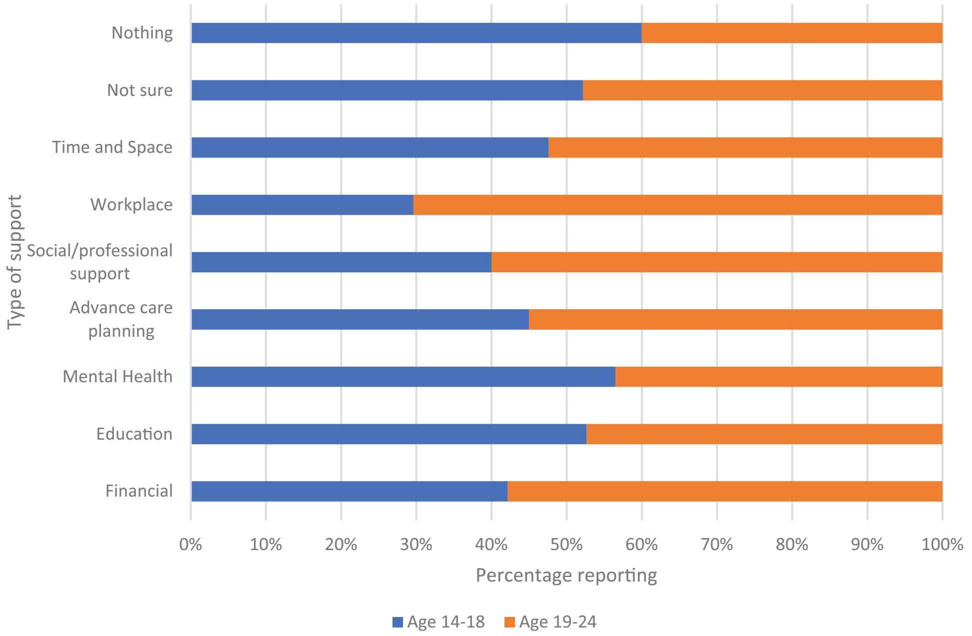


Figure 3. Types of support reported by youth with caregiving experience, by age-group (n = 349).



conversations from health, educational, and social support systems that support youth for potential caregiving responsibilities. Future research should continue soliciting insights from youth to ensure that our policy investments are meaningful for youth now and as they transition to adulthood, and are responsive to the needs they identify from their caregiving experiences alongside their developmental and educational circumstances.

Coordination between health, education systems at multiple levels, and local government or community organizations could facilitate identifying caregivers (eg, through surveys) and the development and dissemination of support programs, educational guidebooks, videos, and workshops to help youth learn to perform various medical tasks (eg, wound care, medication management) and to learn broadly about caregiving responsibilities and self-care. These materials could be developed by caregivers, care receivers, researchers, caregiving organizations (eg, the National Alliance for Caregiving), and health care systems as part of their community outreach programs. These materials could be disseminated in school health classes, advising, or counseling centers, and doctor offices. Policies enabling youth to participate in health care visits could also be critical to their obtaining important information about caregiving, making medical decisions, and managing their mental and emotional health. While involving youth in medical information and decision making could be beyond their developmental readiness, engaging them incrementally could ease the burden associated with the steep learning curve and intense pressure of making sudden medical decisions for a relative without preparation.[29] Meanwhile, some opportunities for minimizing this burden include screening for caregiving and increasing access to remote mental health support services and support groups.[30,31] Screening, for example, could be implemented in the near future through conversations and in the longer-term could be integrated into patient questionnaires or the patient portal. Efforts to foster early engagement in their own health care, particularly during care transitions, could be critical to youth wellbeing.[32]

Policy makers should update FMLA and other workplace policies and financial supports to include the circumstances of young caregivers including in state FMLA expansions that offer paid leave.[19] Data from adults 18 and older suggest that FMLA minimum hours and tenure requirements disproportionately exclude workers who are women, Black, Indigenous, and multiracial.[16,33,34] In fact, the policy also excludes consideration of young caregivers who may be financially responsible for their adult relatives through jobs with lower hours alongside educational responsibilities. These caregivers could benefit from the job security offered by

FMLA so they can return after their caregiving responsibilities. Investing in the wellbeing of young caregivers early on could be critical to preventing health disparities and inequities stemming from socio-structural barriers, later in life.[35] Although respondents age 19 to 24 were more likely to describe a need for workplace support, extending policies to support those who are younger could be beneficial, particularly given recent state level initiatives to draw on youth to address the labor shortage.[36]

Future research should solicit more information about respondents' caregiving experiences, to examine relationships between the types of support identified and the nature of respondents' caregiving experiences. Our study is limited in inferences about caregiving support needs among racial/ethnic minority youth. For instance, youth identifying with communities where mental health disorders are stigmatized may not have identified mental health support.[37] These perspectives should be examined further to ensure the development of policies and other resources that are responsive to the needs of diverse youth.[23]

Given the increasing role of family caregivers in supporting the needs of adults who may be aging or affected by chronic or acute health conditions including COVID-19, policies and programs should develop or extend existing policies to specifically meet the needs of youth who may be current or future caregivers. Supporting youth early on is an investment toward promoting caregivers' health later in life. Using youth-informed approaches is critical to developing relevant and effective policies and resources in the evolving area of caregiving.

The authors thank the MyVoice team for their assistance with developing questions and data collection. We are also grateful to Eve Rubovits for her assistance with developing figures.

To see this article online, please go to: http://jabfm.org/content/35/4/814.full.

References

1. Raj M, Feldman S, Platt JE, Chang T. "If it needs to be done, it needs to be done": National survey of youth experiences and perspectives on caregiving. J Adolesc Heal 2021 Oct;69(4):664–67.
2. Levine C [Internet] More than 1 million young caregivers live In the United States, but policies supporting them are still 'emerging.' Health Affairs Blog, August 7, 2017. Available from: https://www.healthaffairs.org/do/10.1377/forefront.20170807.061390/full/.
3. Levine C, Hunt GG, Halper D, Hart AY, Lautz J, Gould DA. Young adult caregivers: A first look at an unstudied population. Am J Public Health 2005;95(11):2071–5.
4. Hunt G, Levine C, Naiditch L. Young caregivers in the US; 2005. Available from: https://www.caregiving.org/wp-content/uploads/2020/05/youngcaregivers.pdf.
5. Bevans M, Sternberg EM. Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. JAMA 2012;307:398–403.
6. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. JAMA 2014;311:1052–60.
7. Siskowski C. Young caregivers: effect of family health situations on school performance. J Sch Nurs 2006;22(3):163–9.
8. Williams JC, Devaux R, Petrac P, Feinberg L. Protecting family caregivers from employment discrimination, Report by AARP Public Policy Institute; 2012. Available from: https://cancercaregiversaz.com/wp-content/uploads/2018/05/2016-AARP-Protecting-Family-Caregivers-from-Employment-Discrimination.pdf.
9. Lopez-Anuarbe M, Kohli P. Understanding male caregivers' emotional, financial, and physical burden in the United States. Healthcare 2019;7:72.
10. Doupnik SK, Hill D, Palakshappa D, et al. Parent coping support interventions during acute pediatric hospitalizations: a meta-analysis. Pediatrics 2017;140.
11. Waller A, Dilworth S, Mansfield E, Sanson-Fisher R. Computer and telephone delivered interventions to support caregivers of people with dementia: a systematic review of research output and quality. BMC Geriatr 2017 Nov 16;17(1):265.
12. Lynch J, Cahalan R. The impact of spinal cord injury on the quality of life of primary family caregivers: a literature review. Spinal Cord 2017;55:964–78.
13. Shin JY, Choi SW. Interventions to promote caregiver resilience. Curr Opin Support Palliat Care 2020;14:60–6.
14. Napoles AM, Chadiha L, Eversley R, et al. Developing culturally sensitive dementia caregiver interventions: are we there yet? Am J Alzheimers Dis Other Demen 2010;25:389–406.
15. Schulz R, O'Brien A, Czaja S, et al. Dementia caregiver intervention research: in search of clinical significance. Gerontologist 2002;42:589–602.
16. Raj M, Singer PM. Redefining caregiving as an imperative for supporting caregivers: challenges and opportunities. J Gen Intern Med 2021;36:3844–6.
17. Family and Medical Leave Act [Internet]. U.S. Department of Labor; 2019 (accessed 15 January 2019). Available from: https://www.dol.gov/whd/fmla/.

18. Kavanaugh MS, Stamatopoulos V, Cohen D, Zhang L. Unacknowledged caregivers: a scoping review of research on caregiving youth in the United States. Adolescent Res Rev 2016;1:29–49.
19. Kavanaugh MS, Stamatopoulos V. Young carers, the overlooked caregiving population: introduction to a special issue. Child Adolesc Soc Work J. 2021;38:487–9.
20. Choi H, Heisler M, Norton EC, Langa KM, Cho T-C, Connell CM. Family care availability and implications for informal and formal care used by adults With Dementia In The US. Health Aff 2021 Sep;40(9):1359–67.
21. Feinberg LF. The dual pressures of family caregiving and employment.; 2016. Available from: https://www.aarp.org/content/dam/aarp/ppi/2016-03/The-Dual-Pressures-off-Family-Caregiving-and-Employment.pdf.
22. Leu A, Becker S. A cross-national and comparative classification of in-country awareness and policy responses to 'young carers.' J Youth Stud 2017;20:750–62.
23. Sprague Martinez LS, Yan CT, Augsberger A, et al. Changing the face of health care delivery: The importance of youth participation. Health Aff 2020;39.
24. Lenhart A. Teens and mobile phones over the past five years: Pew internet looks back. Pew Res Cent. 2009; Published online.
25. Lenhart A. *Teens, technology and friendships: Video games, social media and mobile phones play an integral role in how teens meet and interact with friends.*; 2015. Available from: https://www.pewresearch.org/internet/2015/08/06/teens-technology-and-friendships/.
26. DeJonckheere M, Nichols LP, Moniz MH, et al. MyVoice national text message survey of youth aged 14 to 24 years: Study Protocol. JMIR Res Protoc 2017;6:e247.
27. MyVoice Question Bank [Internet]. Hear My Voice Now; 2021 (accessed 17 September 2021). Available from: www.hearmyvoicenow.org/questionbank/.
28. Watkins DC. Rapid and rigorous qualitative data analysis: the "RADaR" technique for applied research. Int J Qual Methods 2017;16:(1–9).
29. Schulz R, Eden J. Family caregiving roles and impacts. In: Schulz R, Eden J, eds. Families caring for an aging America. National Academies Press; 2016.
30. Clarke AM, Kuosmanen T, Barry MM. A systematic review of online youth mental health promotion and prevention interventions. J Youth Adolesc 2015;44:90–113.
31. Cummings JR, Wen H, Druss BG. Improving access to mental health services for youth in the United States. JAMA 2013;309:553–4.
32. Schuiteman S, Chua K-P, Plegue M, et al. Self-management of health care among youth: implications for policies on transitions of care. J Adolesc Health 2020;66:616–22.
33. Heymann J, Sprague A, Earle A, et al. US sick leave in global context: US eligibility rules widen inequalities despite readily available solutions. Health Aff 2021;40(9);1501–9.
34. Chen M. The growing costs and burden of family caregiving of older adults: a review of paid sick leave and family leave policies. Gerontologist 2016;56:391–6.
35. Heymann J, Sprague A. Why adopting a national paid sick leave law is critical to health and to reducing racial and socioeconomic disparities—long past due. JAMA Heal Forum 2021;2.
36. Dean G. Wisconsin's Senate approves a bill allowing 14 year olds to work as late as 11 p.m., and supporters say it could help plug the labor shortage [Internet]. Business Insider; 2021 (accessed 21 October 2021). Available from: https://www.businessinsider.in/policy/economy/news/wisconsins-senate-approves-a-bill-allowing-14-year-olds-to-work-as-late-as-11-p-m-and-supporters-say-it-could-help-plug-the-labor-shortage/articleshow/87186883.cms.
37. Molloy L, Beckett P, Chidarikire S, Merrick TT, Guha M, Patton D. Culture, the Stigma of Mental Illness, and Young People. J Psychosoc Nurs Ment Health Serv 2020;58:15–8.