The presence of perceived stress among primary and non-primary adult child caregivers in the Greater Chicago Area

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Abstract

Background: A wealthy of literature constructed caregiving as a stressful event. This study aims to examine the association between caregiver role and perceived stress by comparing the perceived stress of primary and non-primary adult child caregivers.

Methods: Data were derived from the Piety Study, a community-engaged study of U.S. Chinese adult children who were 21 years and older living in the greater Chicago area. Perceived stress was evaluated by the Chinese Perceived Stress Scale. Linear regression analyses were performed.

Results: Primary adult child caregivers were more likely to be employed ($\chi^2 = 9.00, p < .01$) and have higher income ($\chi^2 = 11.46, p < .01$) than non-primary adult child caregivers. The overall health status between primary adult child caregivers and non-primary adult child caregivers was not significant ($\chi^2 = 3.35, p = .37$). The caregiver role was not significantly associated with perceived stress (Parameter Estimate (PE) = -0.427, Standard Error (SE) = 0.587, $p = .47$).

Discussion: Healthy caregiver hypothesis was supported in this study while we also proposed wealthy caregiver hypothesis. As the number of ageing population largely increased in the past decades, a more balanced and updated profile of family caregivers for older adults is needed to encourage more adult children to assume primary caregiver roles.

Introduction

The stress process model served as the major orientating framework for understanding the consequences of family caregiving in the past decades [1]. The stress process theory constructs family caregiving as a stressful event and family caregivers are associated with negative health outcomes. However, recent studies found better health outcomes in primary caregivers than non-primary caregivers. The healthy caregiver hypothesis has been proposed as an alternative paradigm to explain positive caregiving consequences.

The healthy caregiver hypothesis suggests that old persons who are healthier assume primary caregiver role, leading to better health outcomes in primary caregivers than non-primary caregivers of the same cohort. This hypothesis was supported by studies that found older adults who took over primary caregiver role were physically healthier, and had lower rates of functional decline, cognitive decline and mortality than non-primary caregivers [2-7].

Previous research tested the healthy caregiver hypothesis in old caregivers sample and most of them were spouse caregivers. However, healthy caregiver hypothesis has rarely been tested in adult child caregivers. Adult children constitute the largest group of primary caregivers around the globe. For example, 42% of primary caregivers were adult child caregivers in the United States [8]. Particularly, the proportion of Chinese immigrants in the U.S. who assume primary caregiver role for ageing parents may be overwhelmingly high due to its relevance in Chinese culture.

Whether U.S. Chinese adult child caregiver would follow the stress process model or healthy caregiver hypothesis remains unclear. Primary adult child caregiver may experience high stress during caregiving process as they regard providing care for ageing parents as extra work in their daily life [9,10]. Some research indicated the collectivistic cultural values such as familism would attenuate stress appraisal [11]. In Chinese culture, adult children are more likely to regard caregiving as a normal part of daily life rather than sacrifice [12]. However, the stress experienced in taking care of ageing parents for U.S. Chinese adult children immigrants may be different from those who stay in China. Cultural values may shift with immigration to the U.S. [13,14]. Adult children are generally able to adapt easier to Western culture and may endorse such western ideologies as individualism.

Early studies on family caregiving have largely utilized samples composed exclusively of primary caregivers, which makes it difficult to identify whether high levels of stress was emanating from caregiving [15,16]. Research on both primary caregivers and non-primary caregivers can demonstrate more clearly how informal caregiving experiences affect the perceived stress of primary caregivers.

In this study, we aim to: 1) describe the prevalence of perceived stress in a community-dwelling population of U.S. Chinese adult children; 2) examine the reliability of the Chinese Perceived Stress Scale.
among U.S. Chinese adult children; and 3) investigate the association between primary caregiver role and the perceived stress among U.S. Chinese adult children.

**Methods**

**Sample**

The Piety Study is a community-engaged study of U.S. Chinese adult children living in the greater Chicago area. Adult children aged 21 years and older, and having at least one parent who is Chinese aged 60 years and older were eligible to participate in the study. Primary adult child caregivers were defined as the adult children who assuming the primary caregiver role for mother or father. Non-primary adult child caregivers referred to those who were neither the primary caregiver for their mother nor for their father. The sample size was 548. Face-to-face home interviews were conducted by trained multicultural and multilingual interviewers. Preferred language (English or Chinese) and dialect (e.g. Cantonese, Taishanese, Mandarin, and Teochew) for participants were used during the interview.

**Measurements**

**Sociodemographics:** Basic demographic information collected included age, sex, education, annual personal income, marital status, employment status, quality of life and general health. Education was measured by the years of education completed. Self-reported annual income was divided into four groups: 1) $0–$4,999 per year; 2) $5,000–$9,999 per year; 3) $10,000–14,999 per year; and 4) more than $15,000 per year. Overall health status was assessed by self-reporting, based on the four-point scale (1 = very good, 2 = good, 3 = fair, 4 = poor). Quality of life was assessed by asking "In general, how would you rate your quality of life?" and the answer was based on a four-point scale (1 = very good, 2 = good, 3 = fair, 4 = very good).

**Perceived stress:** Individual's appraisal of a situation as stressful is regarded as the best indicator of the experience of stress [17]. Perceived Stress Scale was widely used to evaluate the degree to which participants perceived their lives as being unpredictable, uncontrollable, and overloading [18,19]. In this study, the Chinese Perceived Stress Scale (PSS-10) was adopted to evaluate the degree of perceived stress among Chinese adult children caregivers. Respondents indicated their answers using a 5-point scale (0 = never, 1 = almost never, 2 = fairly often, 3 = fairly often, 4 = very often). After recoding the items in the same direction, we added up the ten items, with higher scores indicating higher perceived stress. Content validity of PSS-10 has been examined by previous research. A study in the U.S. revealed internal reliability score (Cronbach’s alpha) on the PSS-10 was .88 among Alzheimer’s disease caregivers [15]. The PINE study reported internal reliability score (Cronbach’s alpha) on the PSS-10 was .86 among U.S. Chinese older adults [20].

**Data analysis**

Descriptive analyses were used to describe the general socio-demographic characteristics of primary and non-primary adult child caregivers. Chi-squared tests were used to evaluate socio-demographic differences between participants. Linear regression models were used to examine whether perceived stress levels were associated with age, sex, education, annual personal income, marital status, employment, quality of life, general health and primary caregiver role. Statistical analyses were conducted using SAS, V9.2 (SAS Institute Inc., Cary, NC).

**Results**

**Characteristics of the study sample**

In the present study sample, 393 were primary adult child caregivers for their ageing parents and 149 were non-primary adult child caregivers (Table 1). With regard to primary adult child caregivers, the majority of them were female (64.89%), married (79.90%) and employed (86.01%). Most of them aged 35 to 49 (51.15%), with an education level between 7 to 12 years (55.22%), reported good quality of life (53.18%) and good overall health status (51.65%), and had an annual income between $5,000 to $9,999 (34.87%).

As for non-primary adult child caregivers, the majority of them were female (65.77%), married (85.23%) and employed (75.17%). The largest proportion of them were between 35 to 49 (50.34%), with an education level between 7 to 12 years (62.42%), reported good quality of life (55.03%) and good overall health status (48.99%), and had an annual income between $0 to $4,999 (36.91%).

Table 1. Demographic characteristics of adult children by primary caregiver role.
Chi square test was conducted for comparing the differences of demographic factors between primary and non-primary adult child caregivers. The results showed education ($\chi^2 = 12.52, p < .05$), employment status ($\chi^2 = 9.00, p < .01$) and income ($\chi^2 = 11.46, p < .01$) were significantly different between groups. Primary adult child caregivers were more likely to be employed and have higher income than their counterparts.

**Scale reliability**

In our sample, the alpha coefficient of reliability for PSS-10 was .83. The ten items in the scale were significantly correlated (Table 2). However, item 7 that being able to control irritations in life showed a weaker correlation with other items in the scale. If we delete item 7, the alpha would slightly increase to .84. Compared with other items in PSS-10, upset because something happened unexpectedly and unable to control important things had higher inter-item correlation coefficients.

**Prevalence of perceived stress by primary and non-primary adult child caregivers**

Table 3 shows the prevalence of perceived stress by primary caregiver and non-primary caregiver. Among primary adult child caregivers, 92.88% of them have experienced some level of stress. The largest proportion of participants (33.34%) sometimes, fairly often, or often felt they could not cope with all the things had to. Of the four items worded in a positive direction, never or almost never able to control things had higher inter-item correlation coefficients.

**Perceived stress scale**

The association between the primary caregiver role and perceived stress is presented in Table 4. The caregiver role was not significantly associated with perceived stress. Employment status and income were significantly associated with perceived stress of adult children. The largest number of non-primary adult child caregivers (12.47%).

**Association between primary caregiver role and perceived stress**

Overall, 93.04% of adult children have perceived some form of stress in their daily lives. Adult children who were younger, female, had higher education and poorer health status were more likely to perceive higher levels of stress. As for primary caregivers, we found that 92.88% have experienced some level of stress in their daily lives. With regard to non-primary caregivers, 94.63% perceived some form of stress in their daily lives. However, the caregiver role was not significantly associated with perceived stress. Employment status and income were significantly different between primary and non-primary adult child caregivers.

**Discussion**

Among non-primary adult child caregivers, 94.63% perceived some form of stress. The largest number of non-primary adult child caregiver (30.88%) sometimes, fairly often, or often felt nervous and stressed. Of the four items worded in a positive direction, never or almost never able to control irritations in life was most commonly reported by non-primary adult child caregivers (13.42%).

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**Table 2. Perceived stress scale item correlation coefficients.**

| Perceived Stress Scale Items | Alpha if item deleted | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|-----------------------------|----------------------|---|---|---|---|---|---|---|---|---|---|
| 1.Upset because something happened unexpectedly | 0.8 | 1 |
| 2.Felt unable to control important things | 0.8 | .56*** | |
| 3.Felt nervous and stressed | 0.8 | .55*** | .53*** | 1 |
| 4.Confident about the ability to handle personal problems | 0.82 | .26*** | .26*** | .27*** | 1 |
| 5.Felt things were going your way | 0.82 | .29*** | .27*** | .40*** | .40*** | 1 |
| 6.Could not cope with all the things had to | 0.81 | .38*** | .45*** | .40*** | .26*** | .23*** | 1 |
| 7.Been able to control irritations in life | 0.84 | .15*** | .12*** | .13*** | .19*** | .18*** | .16*** | 1 |
| 8.Felt you were on top of things | 0.81 | .31*** | .27*** | .31*** | .40*** | .44*** | .27*** | .31*** | 1 |
| 9.Angered because things happened out of control | 0.81 | .42*** | .40*** | .44*** | .28*** | .28*** | .44*** | .25*** | .30*** | 1 |
| 10.Felt could not overcome piled up difficulties | 0.8 | .45*** | .49*** | .46*** | .31*** | .28*** | .45*** | .26*** | .32*** | .52*** | 1 |

Note. *p < .05, **p < .01, ***p < .001

**Table 3. Presence of perceived stress by primary caregiver and non-primary caregiver**

| Never (%) | Almost never (%) | Sometimes (%) | Fairly often (%) | Very often (%) |
|-----------|------------------|---------------|------------------|----------------|
| Primary Caregiver | Non-Primary Caregiver | Primary Caregiver | Non-Primary Caregiver | Primary Caregiver | Non-Primary Caregiver | Primary Caregiver | Non-Primary Caregiver | Primary Caregiver | Non-Primary Caregiver |
| 1.Upset because something happened unexpectedly | 61.32 | 61.07 | 13.74 | 17.45 | 16.54 | 16.11 | 6.36 | 4.70 | 2.04 | 0.67 |
| 2.Felt unable to control important things | 64.80 | 61.74 | 16.07 | 12.75 | 13.01 | 14.09 | 5.10 | 9.40 | 1.02 | 2.01 |
| 3.Felt nervous and stressed | 50.64 | 51.01 | 17.30 | 18.12 | 21.12 | 20.81 | 9.16 | 6.04 | 1.78 | 4.03 |
| 4.Confident about the ability to handle personal problems | 1.78 | 2.01 | 2.54 | 5.37 | 12.47 | 16.11 | 41.73 | 45.64 | 41.48 | 30.87 |
| 5.Felt things were going your way | 5.34 | 1.34 | 5.34 | 9.40 | 27.48 | 24.16 | 37.40 | 40.94 | 24.43 | 24.16 |
| 6.Could not cope with all the things had to | 48.35 | 42.95 | 18.32 | 28.19 | 25.70 | 20.81 | 5.60 | 5.37 | 2.04 | 2.68 |
| 7.Been able to control irritations in life | 5.85 | 6.04 | 6.62 | 7.38 | 26.79 | 12.09 | 36.64 | 43.62 | 34.10 | 30.87 |
| 8.Felt you were on top of things | 3.06 | 4.70 | 6.63 | 7.38 | 23.72 | 31.54 | 41.84 | 38.26 | 24.74 | 18.12 |
| 9.Angered because things happened out of control | 52.93 | 53.69 | 22.39 | 22.82 | 20.83 | 19.46 | 3.05 | 2.68 | .76 | 1.34 |
| 10.Felt could not overcome piled up difficulties | 64.89 | 63.76 | 22.39 | 25.50 | 9.92 | 8.05 | 2.29 | 1.34 | .51 | 1.34 |

**Table 4.**
Our study found adult children who were primary caregivers were more likely to have a job and have higher income. This is in contrast with prior studies that suggested competing roles of adult children create time constraints that detract from the ability to provide care and in particular, participation in the labor force appears to reduce caregiving to parents [29-31]. Some studies also found similar results that employment was not associated with primary caregiver role of adult children [32]. Based on our results, we proposed healthy caregiver hypothesis to suggest the portrayal for primary caregiver would not always be in poor health with low income. However, this hypothesis needs to be tested in future research.

Conclusions

In sum, the present study identified adult children who were primary caregivers were more likely to have a job and have higher income. Primary caregiver role was not significantly associated with perceived stress. Health status was not significantly different between primary and non-primary adult child caregivers. As the number of ageing population largely increased in the past years, a more balanced and updated portrayal of family caregivers for older adults is needed to encourage more adult children to assume primary caregiver role and provide care for their ageing parents.

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Table 4. Perceived stress regression model estimated parameter.

|                   | Model A | Model B | Model C |
|-------------------|---------|---------|---------|
|                   | b (SE)  | b (SE)  | b (SE)  |
| Age               | -0.047 (.026) | -0.045 (.029) | -0.068 (.028)* |
| Female            | 1.390 (.566)* | 1.587 (.564)** | 1.517 (.547)** |
| Income            | -0.276 (.131)* | -0.249 (.128) |
| Married           | -0.863 (.493) | -0.678 (.673) |
| Education         | -0.252 (.085)** | 0.295 (.084)** |
| Employed          | -1.884 (.837)*** | -1.431 (.815) |
| Quality of life   | -0.768 (.398) |
| General health    | 2.084 (.378)** |
| Primary caregiver role | -0.541 (.607) | -0.410 (.606) | -0.427 (.587) |

Note: *p < .05, **p < .01, ***p < .001

Consistent with previous research, our study found adult children who are younger, female, with higher education and poorer health status were more likely to perceive higher levels of stress [21,22]. Whereas, in the corresponding PINE study, which also used PSS-10 to examine the perceived stress among U.S. Chinese older adults, respondents with an older age were more likely to report higher levels of stress [20,23]. This may be explained as that as for older adults, old age was associated with deterioration in health and thus resulted in perceiving higher levels of stress. But for adult children, they have competing roles and have more difficulty with accepting that their parents are becoming older. Based on the adaptation theory, adult children would adapt to the stress in life over time. Their perceived stress would decline thereafter as a result of adaptation process and then filial maturity was attained [22].

In contrast to prior studies, this study demonstrated that there was no correlation between primary caregiver role and perceived stress [15]. The stress and coping model indicates primary caregivers are associated with higher levels of perceived stress resulting from the impairments of care recipients and caregiver involvement [17,24]. Most prior studies examined the perceived stress of primary caregivers and confirmed primary caregivers were associated with high stress [25]. However, the general stress and caregiving-related stress were difficult to distinguish by only focusing on primary caregivers. Our study goes beyond the existing literature by comparing primary adult child caregivers with non-primary adult child caregivers, and found primary caregiver role was not significantly associated with perceived stress. It may be explained that the perceived stress of adult children mainly comes from other sides of their life, such as work and raising children, rather than taking care of their ageing parents. Additionally, high levels of familialism would result in the appraisal of caregiving for ageing parents as less burdensome [11]. Chinese adult children have a strong sense of filial obligation and perceive taking care of ageing parents as a normal part of their life [26]. Previous research on Chinese immigrant sample also found providing caregiving for ageing parents can generate reward and mitigate burden for adult children [27,28].

Our study found the overall health status between primary and non-primary adult child caregiver was not significant. Previous studies suggested primary caregivers were more likely to have poor physical health outcomes when compared with non-primary caregivers [25,29]. It is probably because those studies only focus on primary caregivers or based on non-representative samples that over-represent certain number of caregivers with poor health. Some studies reported negative effects of caregiving on physical health are most likely to be found in psychologically distressed dementia caregivers [21]. In addition, healthy caregiver hypothesis has been supported by prior studies on spouse caregivers, while our study extends existing understanding of healthy caregiver hypothesis by applying it to adult child caregivers.
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