# Redefining caregiver strain for family caregivers in end-of-life care in Hong Kong

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### Abstract

**Objectives.** Caregiving for family members at their end of life is stressful. Caregivers' strain, burden, or stress has been measured in various geographical and sociodemographic contexts. The concept of stress, burden, and strain are sometimes used interchangeably. By analysing the factor structure of the Chinese version of the Modified Caregiver Strain Index (C-M-CSI), this study aimed to examine the caregiving strain concept and its demographic correlates.

**Methods.** A sample of 453 family caregivers of patients with a terminal illness in Hong Kong was employed. Exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) were performed. In addition, generalized linear models (GLM) were used to examine the demographic correlates.

**Results.** The EFA yielded a 3-factor model termed "Perception of Caregiving," "Empathetic Strain," and "Adjustment Demand." This 3-factor model explained 50% of the variance and showed good internal consistency. The CFA confirmed the 3-factor construct with satisfactory internal reliability ($\chi^2$ [61, $N = 226$] = 108.86, $p < 0.001$, CFI = 0.96, TLI = 0.95, SRMR = 0.04, and RMSEA = 0.06). Inspired by this factor structure and concepts of stress and strain from engineering discipline, a new model of caregiver strain is proposed. Additionally, family caregivers of non-cancer patients, who were not living with the patient, or younger were associated negatively with different dimensions of caregiver strain.

**Significance of results.** The results gave insights into the advancement of the conceptualization of caregiver strain, its multidimensional nature, and process of change, which inform directions for future research and practices.

## Introduction

Majority of patients at the end of life, as well as their family caregivers, choose their homes as the preferred place of care (Dittborn et al. 2021; Gerber et al. 2019). With the recent COVID-19 pandemic, there is a growing demand for hospital beds as well as a generalized fear of contracting an infectious disease globally (Fordjour and Chow 2022; Shadmi et al. 2020). Patients with advanced illness therefore spend most of their time at home. Family caregivers are major support systems for this group of patients. In meeting the multidimensional needs of patients, the different demands and responsibilities often induce an enormous level of stress and strain on these caregivers. Family caregivers of terminally ill patients have reported adverse psychological and physical consequences from the burden of care (Onyeneho and Ilesanmi 2021). A previous study by Oechsle et al. (2020) revealed that about 90% of family caregivers of patients facing advanced cancer have clinically relevant distress with common symptoms of exhaustion, sadness, loneliness, and sleep problems. In response to the stress and strain, some use maladaptive coping, which, in return, may cause complicated health issues for the family caregivers. For instance, a considerable number of caregivers have alcohol use and drug use disorders resulting from high care burdens (Webber et al. 2020).

Palliative care has been advocated worldwide to improve the quality of life not only for the patient but also for their family members (World Health Organisation 2020). Psychosocial and educational end-of-life care (EoLC) interventions that are caregiver-focused have been made available globally. Caregiver burden or strain is one of the 5 common outcome measures for caregivers under EoLC intervention (Ahn et al. 2020). The UK Medical Research Council has highlighted the importance of the process evaluation of such complex interventions. Particularly, the mechanism of impact outlining the causal assumptions of the intervening variables with the outcomes is required to be spelled out clearly in the design phase (Moore et al. 2015). For optimal intervention, addressing the caregiver strain and understanding its mechanism of change are essential. Fundamentally, there is also a need to understand what constitutes caregiver strains considering cultural or geographical sensitivity.

Caregiver strain, stress, and burden are often used interchangeably. Thornton and Travis (2003) described stress and burden as the physical and or emotional response to caregiving challenges, whereas strain is defined as the perception of the persistent difficulties that affect the well-being of the caregivers. In most intervention studies for caregivers, strain is considered a unidimensional outcome (Ahn et al. 2020; Chan et al. 2013); yet, caregiving is complex and multidimensional (Thornton and Travis 2003). The caregiver strain index was originally developed by Robinson (1983) as a measure of objective strain to assess caregiver-perceived strain. A study by Rubio et al. (1999) assessed the constructs of the caregiver strain and identified 4 different factors, namely inconveniences, adjustment, upsetting, and work adjustments, which were different from the original study. Thornton and Travis (2003) also examined the reliability of the earlier version of caregiver strain index by Robinson (1983) for applications with contemporary long-term family caregivers in USA.

Building on the earlier version, Thornton and Travis (2003) amended and developed the Modified Caregiver Strain Index (M-CSI), which consists of 13 items, covering the subjective and objective elements of caregiver strain. They proposed a 3-factor model of the M-CSI: perception of caregiving, care–recipient characteristics, and emotional status (Thornton and Travis 2003). The study by developers of M-CSI, Thornton and Travis (2003), also found 3 components in the measurement, but the analysis of correlation with caregiver strain was done as a unidimensional construct. This M-CSI measurement has been translated and applied in various cultures, such as Portuguese (Ribeiro et al. 2021), Chinese (Chan et al. 2013), and Turkish (Ugur and Fadiloglu 2010), to assess caregiver strain. Previous studies have also employed the M-CSI, particularly among family caregivers of patients with different illnesses (Lutz et al. 2022; Muriuki et al. 2021; Sorayyanezhad et al. 2022).

The Turkish version by Ugur and Fadiloglu (2010) identified 4 factors of M-CSI, namely adaptation, upsetting, inconvenience, and overwhelmed. The Portuguese version by Ribeiro et al. (2021) reported a 2-factor model, namely individual experiences of burden and repercussions on the caregiver's life. Contradictorily, a validation study of the Chinese version by Chan et al. (2013) among Hong Kong caregivers distinguished a single-factor model of M-CSI. However, in their study, no confirmatory factor analysis (CFA) was conducted to further validate the structure and compare the findings with different structure models.

From the construct validity, the items in the M-CSI represent very different dimensions. For guiding the development of complex support for caregivers of patients with advanced illnesses, a more rigorous investigation of the measurement leading to the conceptualization of the core outcome construct is needed. This study aims to explore (1) the structural dimension of strain among family caregivers of patients with end-of-life care in Hong Kong and (2) examine the differences in the identified factors between demographic groups. We hypothesized that the structure of family caregivers' strain is multifactorial. Based on the findings from the study, we can propose a clearer concept of caregiver stain, which is distinguishable from caregiver stress or caregiver burden. A multifactorial caregiver strain identified in this study can provide broader domains for screening of high risk sociodemographic groups. Based on the findings from this study, service directions and plans for tailored caregiver-focused psychosocial EoLC interventions can be developed, which conform to the United Nations' health-related Sustainable Development Goals of ensuring healthy lives and promoting well-being for all persons.

## Methods

### *Procedures and study participants*

The data of this study were extracted from a larger evaluation study of a home-based end-of-life care project in Hong Kong. Data from the participants were collected through a self-administered standardized questionnaire. The baseline clinical assessment data from the project inception (January 2016) to December 2018 were utilized, which are also more comparable with the Hong Kong Chinese version by Chan et al. (2013), in terms of the time frame and sample size. Family caregivers of patients diagnosed with a terminal illness with a prognosis of less than 12 months were included. The inclusion criteria of family caregivers were those (1) aged 18 years old and above and (2) identified by the patient as the primary caregiver who provides the main care and thus at the risk of caregiving burden. Paid caregivers such as domestic helpers were excluded from the study as they are not family caregivers.

### *Measures*

Demographic characteristics of family caregivers explored in this study encompass caregivers' age (younger age <60 years vs. older age ≥60 years), gender (0 = male and 1 = female), relationship with the patient (spouse vs. adult child), living with the patient (yes vs. no), average caregiving time per day in hours (≤8 hours daily vs. >8 hours daily), and major diagnosis of the patient (cancer vs. non-cancer).

The Chinese version Modified Caregivers Strain Index (C-M-CSI), validated in Hong Kong by Chan et al. (2013), was used to assess caregivers' strain. The C-M-CSI consists of 13 items on various caregiving challenges, such as "caregiving is a physical strain." Each item was answered by a caregiver on a 3-point response scale: 0 = no, 1 = yes, sometimes, and 2 = yes, always. When used as a scale the total scale score ranged between 0 and 26.

### *Data analyses*

The Kolmogorov–Smirnov test confirmed the data to be normally distributed ($p > 0.05$). Split-half method of data distribution was employed to split the total sample into 2 halves for use separately in the exploratory factor analysis (EFA) and CFA of the 13 items of C-M-CSI. The 2 subsample sizes met the commonly used sample size criterion of "10 subjects per item" for EFA and CFA (Bollen 1989; Goretzko et al. 2021; Watkins 2018). Using the R (version 3.5.3) statistical package, the EFA was estimated by maximum likelihood methods, with oblique Crawford-Ferguson (CF)-varimax rotation used for the first half of the participants ($n = 227$). Given the nested structure of the data, that is, caregivers nested within 4 nongovernmental organizations, sandwich standard error, known as robust standard error, was used (Zhang et al. 2019). Parallel scree plot was employed to ascertain the number of factors to be extracted, and items with a factor loading greater than 0.30 were assigned to each factor (Arcolin et al. 2022).

Following the EFA, a CFA was conducted on data from the second half of the participants ($n = 226$) to confirm the factor structure suggested by the EFA. Using M*plus* (version 8), the CFA model was estimated by robust maximum likelihood methods, which take clustering cases into account (Padgett and Morgan 2021). The model fit of the CFA model was assessed by multiple fit indices, including model Chi-square, comparative fit index (CFI), root mean square error of approximation (RMSEA), and standardized root mean square residual (SRMR). For RMSEA and

**Table 1.** Participants' demographic information

| | EFA sample (N = 227) | CFA sample (N = 226) | Total (N = 453) |
|---|---|---|---|
| Gender | | | |
| Male (%) | 25.1 | 21.7 | 23.4 |
| Female (%) | 74.9 | 78.3 | 76.6 |
| Age | | | |
| Mean (SD) | 56.94 (14.06) | 58.19 (14.22) | 57.57 (14.14) |
| Range | 20–90 | 24–91 | 20–91 |
| Weekly caregiving hour | | | |
| Mean (SD) | 52.72 (48.38) | 50.50 (51.61) | 51.60 (49.90) |
| Range | 1–168 | 0–168 | 0–168 |
| Living with a patient | | | |
| Yes (%) | 70.5 | 72.6 | 71.5 |
| No (%) | 29.5 | 27.4 | 28.5 |
| Relationship with a patient | | | |
| Spouse (%) | 48.4 | 52.8 | 50.6 |
| Adult children (%) | 51.6 | 47.2 | 49.4 |
| Patient with cancer as the major diagnosis | | | |
| Yes (%) | 59.5 | 51.3 | 55.4 |
| No (%)[a] | 40.5 | 48.7 | 44.6 |

[a]Patients with chronic lower respiratory disease, heart failure, renal disease, motor neurone disease, kidney disease, Parkinson's disease, stroke, and dementia.

**Table 2.** EFA factor loadings: 3-factor solution (n = 227)

| | | Perception of caregiving | Empathetic strain | Adjustment demand |
|---|---|---|---|---|
| Q4 | Caregiving is inconvenient | 0.69 | | |
| Q5 | Caregiving is confining | 0.68 | | |
| Q13 | I feel completely overwhelmed | 0.46 | | |
| Q1 | Caregiving is a physical strain | 0.46 | | |
| Q2 | My sleep is disturbed | 0.38 | | |
| Q12 | Caregiving is a financial strain | 0.38 | | |
| Q10 | Some behavior is upsetting | | 0.76 | |
| Q11 | It is upsetting to find the person I care for has changed so much from his/her former self | | 0.73 | |
| Q7 | There have been changes in personal plans | | | 0.71 |
| Q8 | There have been work adjustments | | | 0.59 |
| Q6 | There have been family adjustments | | | 0.56 |
| Q9 | There have been emotional adjustments | | | 0.44 |
| Q3 | There have been other demands on my time | | | 0.30 |
| Cronbach's alpha | | 0.82 | 0.79 | 0.80 |
| Cronbach's alpha for overall M-CSI scale (0.89) | | | | |

SRMR, a value of 0.06 or lower indicates a good fit, while a CFI value of 0.95 or higher is accepted as a good fit (Shi et al. 2022). Additional CFAs were conducted to examine and compare the model fits with the C-M-CSI models identified by previous studies (See Table 3). The internal consistency of the total scale and extracted subscales were tested by Cronbach's alpha for an acceptable coefficient of 0.70 and above (Goretzko et al. 2021). Finally, after the ideal factor structure was determined, generalized linear models (GLM) using the entire sample were performed to explore the demographic correlates with the identified factors of C-M-CSI.

## Results

### Descriptive results

Table 1 presents the descriptive statistics of the total sample of study participants as well as the 2 separate samples used for EFA and CFA. Of the 453 family caregivers, 76.6% were female, with a mean age of 57.57 years (SD = 14.14). They spent approximately 50 hours (per week) on caregiving. About 50.6% of the caregivers had spousal relationships with the patients, while 48.95% of caregivers were adult children of the patients. More than half (55.4%) had cancer patients, while 71.5% lived with the patients. No significant difference in their demographic variables was detected for the EFA and CFA sample.

### EFA results

Initially, the factorability of the C-M-CSI items was investigated. The Kaiser–Meyer–Olkin measure of sampling adequacy was 0.91,

which is well above the commonly recommended threshold of 0.60 (Watkins 2018). Bartlett's test of sphericity was also significant ($\chi^2$ (78) = 2499.12, $p < 0.001$). Examination of the scree plot and eigenvalues (greater than 1.0) yielded a 3-factor solution explaining 50% of the variance for the entire set of variables. After CF-varimax rotation, items with a factor loading greater than 0.30 were considered significant to load on a factor (Watkins 2018).

As shown in Table 2, 3 factors emerged from the 13 items with no double-loading. The first factor was labeled "Perception of Caregiving," which included 6 items, and it explained 22% of the variance. The second factor, which explained 15% of the variance, was labeled as "Empathetic Strain," which only included 2 items. The last factor labeled "Adjustment Demand" involved 3 items, with 13% explained variance. The validity of the 3 factors extracted was assessed using Promax rotation method, which showed good validity with a factor correlation matrix of less than 0.70. Internal consistency for each of the factors, as well as the overall scale, was examined using Cronbach's alpha. The alpha was good, with coefficient above 0.70 for the overall scale and the subscales.

### CFA results

The CFA for the 3-factor solution from the EFA indicated the model as acceptable ($\chi^2$ [62, N = 226] = 125.68, $p < 0.001$,
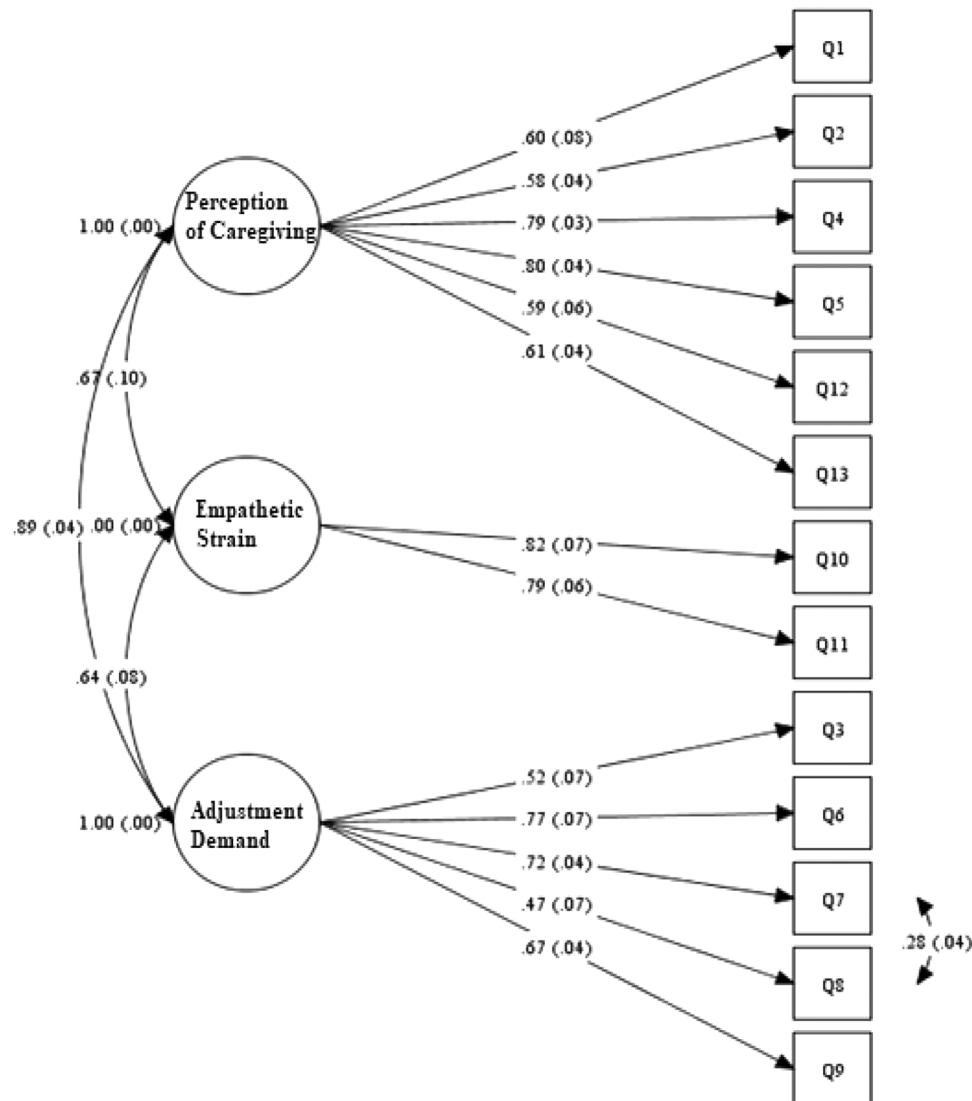
**Fig. 1.** Three-factor CFA of the 13-item M-CSI.

CFI = 0.94, Tucker–Lewis Index [TLI] = 0.93, SRMR = 0.05, and RMSEA = 0.07). Modification indices showed that model fit would improve if residuals between items 7 and 8 correlate. Moreover, both items were loaded on the same factor (i.e., adjustment demand) and were semantically similar. Thus, the revised model added the residual correlation between items 7 and 8, with model fit indices showing a good fit of the data ($\chi^2$ [61, $N = 226$] = 108.86, $p < 0.001$, CFI = 0.96, TLI = 0.95, SRMR = 0.04, and RMSEA = 0.06 [for factor loadings and factor correlations], see Figure 1).

Model fit comparison analyses with models from previous studies are summarized in Table 3. Models 3, 4, and 5 from previous studies indicated poor fit (CFI < 0.90 and RMSEA > 0.08), while Model 2, a 4-factor model, had an acceptable fit. Given that Model 1 (i.e., the 3-factor model of this present study) and Model 2 are not nested, parametric tests, such as Chi-square difference tests, were not used.

A simple comparison of model fit indices showed that Model 1 extracted in this study had a better fit in terms of RMSEA, SRMR, TLI, and CFI. In addition, the 4-factor model in Model 2 includes a single-item factor (work adjustment), which makes it impossible to compute internal consistency reliability using Cronbach's alpha. Furthermore, the adjustment factor of the 4-factor model was found to have low levels of internal consistency with a Cronbach's alpha of 0.66, while, as noted earlier, all the 3 factors of the present study had good internal consistency above 0.70. As a result, the 3-factor model of the present study model was determined to be the best fitting model of C-M-CSI.

### Exploration of correlates

The influential role of caregiver's gender, age, and other factors, such as whether living with the patient, patient health condition, relationship with the patient, and caregiving time were assessed on the identified 3 subscales of the C-M-CSI. Table 4 presents the result of the GLM regression.

The GLM regression analysis revealed that gender had no significant influence on the experience of the various dimensions of caregiver strain ($p > 0.05$). Negative perception of caregiving

**Table 3.** Comparative studies analysis of model goodness of fit indices

|  | Dimensionality |  | $\chi^2$ |  | df | CFI | TLI | SRMR | RMSEA | RMSEA 90% CI |
|---|---|---|---|---|---|---|---|---|---|---|
| Model 1: Present study | 1. Perceptions of caregiving: 1, 2, 4, 5, 12, 13 | Original model | 125.68 | *** | 62 | 0.94 | 0.93 | 0.05 | 0.07 | 0.050–0.084 |
|  | 2. Empathetic strain: 10, 11 | Modified model | 108.81 | *** | 61 | 0.96 | 0.95 | 0.04 | 0.06 | 0.040–0.077 |
|  | 3. Adjustment demand: 3, 6, 7, 8, 9 |  |  |  |  |  |  |  |  |  |
| Model 2: Rubio et al. (1999) | 1. Inconvenience: 2, 3, 4, 5, 6, 7, 9 |  | 118.98 | *** | 49 | 0.93 | 0.92 | 0.05 | 0.08 | 0.061–0.098 |
|  | 2. Upsetting: 10, 11 |  |  |  |  |  |  |  |  |  |
|  | 3. Adjustment: 7, 12, 13 |  |  |  |  |  |  |  |  |  |
|  | 4. Work adjustment: 8 |  |  |  |  |  |  |  |  |  |
| Model 3: Chan et al. (2013) | One factor |  | 200.92 | *** | 65 | 0.88 | 0.86 | 0.06 | 0.10 | 0.081–0.111 |
| Model 4: Ugur and Fadiloglu (2010) | 1. Adaptation: 3, 5, 6, 7 |  | 173.99 | *** | 59 | 0.90 | 0.87 | 0.06 | 0.09 | 0.077–0.109 |
|  | 2. Upsetting: 9, 10, 11 |  |  |  |  |  |  |  |  |  |
|  | 3. Inconvenient: 1, 2, 4 |  |  |  |  |  |  |  |  |  |
|  | 4. Overwhelmed: 8, 12, 13 |  |  |  |  |  |  |  |  |  |
| Model 5: Ribeiro et al. (2021) | 1. Individual experiences of burden: 1, 2, 5, 10, 11, 12, 13 |  | 192.83 | *** | 64 | 0.89 | 0.86 | 0.06 | 0.09 | 0.079–0.110 |
|  | 2. Repercussions on the caregiver's Life: 3, 4, 6, 7, 8, 9 |  |  |  |  |  |  |  |  |  |

Chi-square, Satorra–Bentler scaled Chi-square; df, degrees of freedom; CFI, comparative fit index; TLI, Tucker–Lewis Index; SRMR, standardized root mean square residual; RMSEA, root mean square error of approximation; CI, confidence interval.
***$p < 0.001$.

**Table 4.** The GLM regression result

|  | Perceptions of caregiving ($n = 453$) | | Empathetic strain ($n = 453$) | | Adjustment demand ($n = 453$) | |
|---|---|---|---|---|---|---|
|  | Estimate ($\beta$) | SE | Estimate ($\beta$) | SE | Estimate ($\beta$) | SE |
| Gender (ref. male) | −0.08 | 0.21 | −0.10 | 0.42 | 0.19 | 0.21 |
| Age (ref. younger age <60) | 0.00 | 0.06 | −0.22* | 0.10 | 0.14* | 0.06 |
| Living with the patient (ref. no) | −0.46* | 0.21 | −1.01* | 0.37 | −0.06 | 0.21 |
| Cancer (ref. cancer patients) | 0.70* | 0.29 | 0.18 | 0.13 | 0.82** | 0.26 |
| Spousal caregiver (ref. adult child) | −0.14* | 0.06 | −0.35*** | 0.10 | 0.08 | 0.06 |
| Caregiving time (ref. >8 hours per day) | 0.28*** | 0.06 | 0.37*** | 0.10 | 0.06 | 0.06 |

*$p < 0.05$,
**$p < 0.01$,
***$p < 0.001$.

was positively related to family caregivers of cancer patients ($\beta = 0.70$, $p < 0.05$), who live with the patient ($\beta = 0.46$, $p < 0.05$), who are spouses of the patient ($\beta = 0.14$, $p < 0.05$), and who provide longer caregiving time of more than 8 hours daily ($\beta = 0.28$, $p < 0.001$). Empathetic strain was negatively related to younger family caregivers of ages below 60 years ($\beta = −0.22$, $p < 0.05$), who do not live with the patients ($\beta = −1.01$, $p < 0.05$), who have no spousal relationship with the patient ($\beta = −0.35$, $p < 0.05$), and who provide few hours of care daily (<8 hours) ($\beta = −0.37$, $p < 0.001$). Adjustment demand had positive relation to caregivers of cancer patients ($\beta = 0.82$, $p < 0.01$) and younger family caregivers aged below 60 years ($\beta = 0.14$, $p < 0.05$).

## Discussion and implications

### Constructing the structural dimension of strain

This study's primary goal was to examine the structure of the C-M-CSI by Chan et al. (2013) using a sample of Hong Kong Chinese family caregivers of patients with terminal illness. The factor analyses discovered a new 3-factor model, namely the perception of caregiving, empathic strain, and adjustment demand. The reliability tests confirmed the total scale (0.89) and the 3 subscales (perception of caregiving – 0.82; adjustment demand – 0.80, and empathetic strain – 0.79) have good internal consistency reliabilities. The single factor of C-M-CSI for caregivers of chronically ill patients identified by Chan et al. (2013) also found a Cronbach's
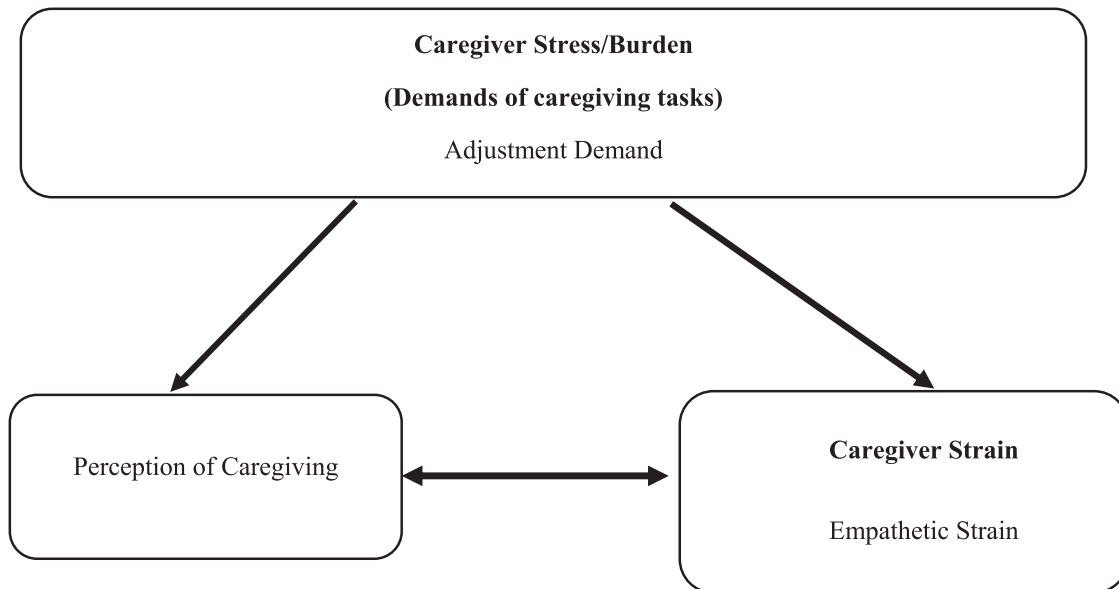
**Fig. 2.** Conceptualization of caregiver strain.

alpha of 0.91. Consistent with the original validation study of caregiver strain index (Robinson 1983) and the modified version by Thornton and Travis (2003), the result from this study suggests that caregiver strain is a multidimensional concept. Comparison of the model fit indices with previous studies gave evidence that in the Hong Kong context, the three-factor model captures family caregivers' strain more appropriately than the unidimensional model proposed by Chan et al. (2013).

With reference to the 3 different dimension items included in the factors, perception of caregiving is the appraisal which was value laden. This finding might be affected by past and current experiences or deliberation of family or cultural values. The second factor, empathetic strain, describes the emotional reactions to witnessing the changes or behaviors of patients, which is specific to the caring recipient and is more contingent. The last factor, adjustment demand, though it is also contingent, portrays the purposive accommodation of the caring role by changing daily functioning. More important of all, all these are carrying a negative connotation. The identified factors share some commonalities with previous studies about caregivers' strain by capturing the perception, the emotional aspects (Robinson 1983), and adaptation issues (Rubio et al. 1999; Ugur and Fadiloglu 2010). Moreover, compared to a general claim of the emotional aspect, empathetic strain is more accurate in summarizing the related items and more specific to the group of caregivers. In our study, there are no overlapping components, which makes our generated 3-factor caregiver strain model a good fit.

### Differentiation of the concept of stress, burden, and strain

Concepts of stress and strain have been defined and applied in the field of mechanical engineering for a long time. Stress is described as the force applied per unit area, whereas strain is the amount of deformation caused by the stress, which is divided by the initial dimension (Collins 2019). Stress and strain are thus different, though they have related concepts. When Thornton and Travis (2003) reviewed the measurements of stress, strain, and burden used in caregiving research, they found that the terms stress

and strain have been used interchangeably without a commonly accepted definition. They attempted to define stress and burden as the physical or emotional response to challenges in the caregivers, while strain was described as the caregiver's perception of the enduring problems or an altered state of their well-being. The researchers then developed the M-CSI (Thornton and Travis 2003), which has been explored in various cultures as mentioned earlier.

The M-CSI has still been used interchangeably to measure caregiving stress, strain, or burden. For example, in the study by Saimaldaher and Wazqar (2020), the M-CSI was used as the measure of caregivers' stress, instead of caregivers' strain. There is also the concern of whether stress or strain should be defined in terms of the person, the environment, or both (Hart 2001). Despite the theoretical congruence in some literature, strain, burden, and stress are distinct concepts.

### Redefining the concept and measurement of caregiver strain

Borrowing from the engineering concepts of stress and strain, we propose to define stress as the external demands in caregiving and strain as the responses or changes of the caregivers after the exposure to stress. This new conceptualization, depicted in Figure 2, offers a clearer process of change, with caregiver stress as the external force, which brings about the changes in various forms of caregiver strain and consequently affects the health outcomes and quality of life of the caregiver.

Following the new conceptualization, the factor of adjustment demand is considered as the caregiver burden or stress, whereas the empathetic strain is the caregiver strain, which is emotional in nature. The factor of perception of caregiving is considered as an element that affects the caregiver strain but being affected by the caregiving stress. The relation between perception of caregiving and actual strain may be bidirectional. Moreover, the demands of the caregiver tasks, including the adjustment factor, are considered as stress, which are the external forces exerted on the caregivers. Some studies have also reported positive outcomes of stress in caregiving among family caregivers (Lindeza et al. 2020; Zhong et al. 2020).

If the definition of caregiver strain is the change in the individual after resuming the caregiver role, then this study postulates that caregiver strain would have negative, neutral, and positive dimensions. These can be valuable directions for future research.

### Identifying sociodemographic factors associated with caregiver strain

Our study found that the experiences of the 3 subscales of C-M-CSI differed among family caregivers' sociodemographic characteristics. This study revealed that the level of empathic strain, adjustment demand, and negative perception of caregiving did not differ by caregivers' gender. Notwithstanding, significant differences were revealed in some caregivers' sociodemographic characteristics. Notably, family caregivers for patients with terminal cancer exhibited higher levels of negative perception and adjustment demand than their counterparts who cared for non-cancer patients. Indeed, previous studies (Lippiett et al. 2019; Thana et al. 2021) indicated that cancer patients have complex needs for treatment, and thus caregiving for cancer patients is demanding. A study by Starr et al. (2022) also postulated that the vast majority of family caregivers with cancer patients experienced moderate to severe sleep disturbance but were hesitant to take the prescribed sleep medication due to their caregiving responsibilities. Similarly, other studies attributed high caregiving demands on family caregivers of cancer patients to the decline in health status and financial well-being of the caregivers (Junkins et al. 2020; Zavagli et al. 2022). These give adequate reasons why the level of the negative perception and adjustment demands subscales were greater for family caregivers of cancer patients.

Family caregivers of ages below 60 years were more likely to experience adjustment demand, as they often have to fulfill other family duties (e.g., childrearing) or work-related responsibilities, which may generate inter-role conflicts (Boumans and Dorant 2021). Unlike the perception and adjustment subscale, the result indicates that irrespective of the types of illness of the patients being cared for, caregivers share a universal empathetic strain. This sheds more light on the care of caregivers. Instead of focusing on the physical and practical supports to the caregivers, which most caregiver support programs do (Hudson et al. 2020), there is universal emotional suffering faced by the caregivers of patients with a terminal illness, which should not be overlooked. The results also revealed that longer caregiving time of more than 8 hours daily leads to higher levels of empathetic strain. However, younger family caregivers of ages below 60 years who do not live with the patient have less level of empathetic strain.

We recommend that health professionals in Hong Kong and to some extent globally should pay critical attention to these higher risk sociodemographic groups and assess their caregiving strain considering the domains of their perception of caregiving, empathetic strain, and adjustment demand. This will protect the higher risk family caregivers from adverse mental, psychosocial, and physiological consequences resulting from caregiving.

### Conclusion

This study critically examined the slippery concept of caregiver strain and offered a precise and distinct new definition ideologized from the engineering discipline. It offers a new differentiation between caregiver stress, burden, and strain, which provides a logical explanation of the controversies of outcomes of caregiver strain in the available studies. Based on the new conceptualization proposed in this study, the caregiver strain is defined as the reactions to the caregiving stress or demands. It can include other emotional reactions, such as the feeling of being torn, or other positive ones, such as contentment. Additionally, physical reactions such as fatigue and hypervigilance can be included. Further qualitative studies of the reactions of caregivers toward caregiving demands and stress can offer more insights in this area.

The new conceptualization advances future studies in examining the consequences of caregiver strain that will offer new directions for handling the negative consequences. The advancement in this theoretical conceptualization and empirical study may inform the development of EoLC interventions tailored to different subgroups of family caregivers to ensure their health and well-being, which are in conformity with the United Nations' health-related Sustainable Development Goals. More research should be carried out to explore the emotional suffering as well as the changes in emotion or emotional strain of the caregivers. Specifically, empathetic emotional pain resulting from the suffering and change in patients' conditions should be critical targets for emotional caring practice or research.

The study has a limitation. The sample of this study involved a homogenous sample of Chinese family caregivers of patients with terminal illness, which will limit the generalizability of the factor structure of M-CSI found in this study to caregivers of other target groups with different cultural backgrounds, as portrayed by the different factor structures of M-CSI reported in previous studies. Despite the limitations, the study sheds light on future research to further refine the concept of caregiver strain and its relationship with stress by taking into account family caregivers with diverse cultural backgrounds.

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