

Factors associated with health literacy among caregivers of patients with advanced cancer: a cross-sectional path analysis using structural equation modelling

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Abstract

Background

Family caregivers of patients with advanced cancer undertake complex information, symptom-monitoring and communication tasks. This study examined caregiver health literacy and pathways linking caregiver burden, self-efficacy, health anxiety and health literacy.

Methods

A cross-sectional survey was conducted with 280 family caregivers recruited from a tertiary hospital in Hangzhou, China, from April to July 2024. Data were collected using a general information questionnaire and validated measures of caregiver health literacy, caregiver burden, general self-efficacy and health anxiety. Associations were examined using univariate tests, Spearman correlations, multiple linear regression and structural equation modelling with robust maximum likelihood estimation.

Results

The mean total caregiver health literacy score was 139.02 (standard deviation 16.67). Health literacy differed by age, occupation, residence, education, relationship to the patient, monthly income and self-rated health status ($P < 0.05$). In multiple regression, education, caregiver burden and self-efficacy were independently associated with health literacy. The final structural model had acceptable fit (robust CFI = 0.921, robust TLI = 0.912, robust RMSEA = 0.063 and SRMR = 0.056). Caregiver burden had a negative path to health literacy ($\beta = -0.189$, $P = 0.013$), whereas self-efficacy had a positive path ($\beta = 0.374$, $P < 0.001$). The path from health anxiety was not statistically significant ($\beta = 0.037$, $P = 0.644$).

Conclusions

Caregiver burden and self-efficacy were associated with health literacy among caregivers of patients with advanced cancer. Nursing assessment and education should account for caregivers' educational resources, burden and confidence in care tasks. Longitudinal and multicentre studies are needed before causal interpretations can be made.

Background

Cancer remains a major global health burden. An estimated 19.96 million new cancer cases and 9.74 million cancer deaths occurred worldwide in 2022, and the annual number of new cases is projected to rise substantially by 2050 [1]. China accounted for approximately 4.82 million new cases and 2.57 million deaths in 2022 [2]. As disease progresses, patients and families must manage complex treatment information, symptoms, uncertainty and decisions across hospital and home settings.

Family caregivers are central to this work. They may coordinate appointments, interpret clinical information, monitor symptoms and adverse events, support medication and nutrition management, communicate patient preferences and decide when professional help is required. Cancer caregiving can require substantial time [3], and differences in caregiver communication patterns are associated with variation in cancer-specific health literacy domains [4]. Through these activities, family involvement can support self-management by reinforcing information, identifying problems early and helping patients follow care plans; however, limited understanding, high burden or ineffective communication can also impede self-management and delay help-seeking.

Caregiver health literacy refers to the capacity to find, understand, appraise and use health information for the care recipient and for the caregiver's own wellbeing. Evidence from cancer-caregiver research indicates that health literacy is related to information seeking, communication, understanding care-recipient preferences, navigating health services, burden and self-efficacy [4, 5]. A systematic review found that caregiver health-literacy interventions have mainly addressed understanding disease and treatment, day-to-day care, self-care and engagement with health professionals, while broader interpersonal and health-service determinants have received less attention [6]. These findings are directly relevant to nursing practice because nurses frequently provide symptom education, discharge teaching, teach-back, care coordination and follow-up support.

Recent studies have begun to examine determinants and outcomes of health literacy among cancer caregivers. Moore and colleagues reported domain-specific associations of health literacy with burden, distress and self-efficacy [5], while Park and colleagues used structural equation modelling to study health literacy and caregiver outcomes before radiotherapy [7]. Nevertheless, evidence remains limited for caregivers of adults with advanced cancer in Chinese settings, and few studies have examined caregiver burden, self-efficacy and health anxiety simultaneously within a cancer-specific health-literacy path model. Clarifying these associations may help nurses identify caregivers who need more intensive education and support and may indicate modifiable targets for future interventions.

This study therefore aimed to describe health literacy among caregivers of patients with advanced cancer, identify associated demographic and caregiving factors, and examine structural paths linking caregiver burden, self-efficacy, health anxiety and health literacy. We hypothesised that caregiver burden and health anxiety would be negatively associated with health literacy, whereas self-efficacy would be positively associated with health literacy.

Methods

Study design and setting

This cross-sectional study was conducted in the Department of General Surgery of a tertiary hospital in Hangzhou, China, from April to July 2024. Reporting was prepared with reference to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidance.

Participants

Convenience sampling was used to recruit family caregivers of patients with advanced cancer. For this study, advanced cancer was operationally defined as a pathologically confirmed malignant tumour at clinical stage III or IV. The unit of analysis was the caregiver. An eligible caregiver was an unpaid family member who provided care for at least four hours per day. When more than one family member independently met the eligibility criteria for the same patient, each eligible caregiver could participate; 17 patient identifiers were each linked to two distinct caregivers.

Patients were eligible if they were aged 18 years or older, met the disease-stage definition, had at least one eligible family caregiver and agreed to participate. Patients who were unaware of their cancer diagnosis were excluded. Caregivers were eligible if they were aged 18 years or older, provided unpaid daily care for at least four hours, had sufficient cognitive and communication ability to complete the survey and volunteered to participate. Caregivers with serious physical illness, psychological disorder or intellectual impairment that prevented questionnaire completion, and vulnerable individuals unable to understand the questionnaire, were excluded.

Sample size

Structural equation modelling was the principal analytical method. An RMSEA-based power calculation based on the originally proposed model (27 observed variables and 316 degrees of freedom) used $\alpha = 0.05$, power = 0.80, H_0 : RMSEA = 0.05 and H_1 : RMSEA = 0.08, and indicated a minimum sample of 64. The final re-estimated model contained 65 free parameters and 313 degrees of freedom; applying the same assumptions would require 65 participants, well below the analysed sample of 280. To improve estimation stability, support subgroup comparisons and allow for invalid questionnaires, 336 questionnaires were distributed.

Measures

The general information questionnaire collected caregiver sex, age, education, current or pre-retirement occupation, marital status, residence, relationship to the patient, monthly income, self-rated health, duration of caregiving and chronic disease status.

The Chinese Health Literacy Scale for Caregivers of Cancer Patients was used to assess caregiver health literacy [8]. It contains 44 items across 10 dimensions. Higher scores indicate greater caregiver health literacy. In this sample, Cronbach's alpha was 0.952.

The Family Caregiver Burden Scale for Cancer Patients, developed by Li and colleagues, contains 29 items and was used to assess caregiving burden [9]. In this sample, Cronbach's alpha was 0.939.

The 10-item General Self-Efficacy Scale, developed by Schwarzer and colleagues and translated and validated in Chinese by Wang and colleagues, was used to assess perceived self-efficacy [10,11]. Higher scores indicate greater self-efficacy. In this sample, Cronbach's alpha was 0.918.

The 18-item Chinese Short Health Anxiety Inventory, based on the instrument developed by Salkovskis and colleagues and subsequent Chinese adaptations, was used to assess health anxiety [12-14]. Higher scores indicate greater health anxiety. In this sample, Cronbach's alpha was 0.943.

Data collection and quality control

Eligible caregivers received an explanation of the study and completed the questionnaires after providing informed consent. Data were double-entered and checked for accuracy. Of 336 distributed questionnaires, 306 were returned. During the original on-site quality review, 26 returned questionnaires were excluded because they contained substantial missing responses or internally inconsistent responses; item-level data from these excluded questionnaires were not retained. The remaining 280 questionnaires were included in the analysis.

Statistical analysis

Descriptive, univariate, correlation and multiple regression analyses were conducted using SPSS version 29.0. The distribution of the total health literacy score was assessed using plots, skewness and kurtosis. Independent-samples t tests were used for two-group comparisons. One-way analysis of variance was used for comparisons involving more than two groups when the homogeneity assumption was met; Welch's analysis of variance was used when variances were unequal. Spearman correlation coefficients were calculated for scale scores and health-literacy dimensions. Variables associated with health literacy in univariate or correlation analyses were entered into a multiple linear regression model. Nominal multicategory variables were represented using indicator variables; variance inflation factors were examined for multicollinearity. Structural equation modelling was performed in R version 4.4.3 using lavaan version 0.7-2.

Structural equation modelling was used to estimate paths from caregiver burden, self-efficacy and health anxiety to caregiver health literacy. The three exogenous caregiver constructs were allowed to covary because burden, self-efficacy and health anxiety are theoretically related. Robust maximum likelihood estimation was used to reduce sensitivity to non-normality. Model fit was evaluated using the scaled χ^2/df , robust RMSEA with its 90% confidence interval, robust CFI, robust TLI and SRMR. Five residual covariances were specified between health-literacy domains 1 and 2 and domains 9 and 10, and between self-efficacy items 1 and 2, items 4 and 5, and items 8 and 9; these were retained from the prior model only when supported by modification indices and conceptual overlap. Unstandardised estimates, robust standard errors, standardised coefficients, two-sided P values and 95% confidence intervals were

reported. Because the design was cross-sectional, paths were interpreted as modelled associations rather than causal effects.

Use of generative artificial intelligence

Generative artificial intelligence tools were used for language editing and journal-format preparation only. The authors reviewed and approved the final manuscript and remain responsible for the accuracy, integrity and originality of the work.

Results

Participant characteristics

A total of 336 questionnaires were distributed and 306 were returned (return rate 91.07%). After 26 questionnaires with substantial missing responses or internally inconsistent responses were excluded, 280 valid questionnaires remained (effective response rate 83.33%). These 280 records represented 280 distinct caregivers; 17 patients each contributed two different eligible caregivers. The mean caregiver age was 50.79 years (SD 14.21; range 18-78), and 62.5% were women. Participant characteristics are shown in Table 1.

Caregiver health literacy

The mean total health literacy score was 139.02 (SD 16.67; range 92-181), corresponding to a mean item score of 3.16 (SD 0.38). Domain scores are reported in Additional file 1: Table S1. In the absence of a validated diagnostic cut-off for this scale, the observed score was not categorised as adequate or inadequate.

Univariate associations

Health literacy differed by age, occupation, residence, education, relationship to the patient, monthly income and self-rated health status ($P < 0.05$). Differences by sex, marital status, religious belief, chronic disease and duration of caregiving were not statistically significant. Full results are provided in Additional file 1: Table S2.

Multiple linear regression

The overall regression model was statistically significant ($F = 7.477$, $P < 0.001$) and explained 23.2% of adjusted variance in total health literacy. Education ($\beta = 0.178$, $P = 0.024$), caregiver burden ($\beta = -0.176$, $P = 0.002$) and self-efficacy ($\beta = 0.310$, $P < 0.001$) were independently associated with health literacy.

Variance inflation factors ranged from 1.108 to 2.241, providing no indication of serious multicollinearity (Table 2).

Correlations

Caregiver burden was negatively correlated with total health literacy and most health-literacy domains. Self-efficacy was positively correlated with total health literacy and all domains. Health anxiety was negatively correlated with total health literacy (Spearman's $\rho = -0.185$, $P < 0.01$) and with several domains, including health-professional-supported understanding, social support, understanding patient needs and preferences, processing health information and active engagement with health professionals (Additional file 1: Table S3).

Structural equation model

The base model, which allowed the three exogenous caregiver constructs to covary but did not include residual covariances, had scaled $\chi^2(318) = 930.444$, robust RMSEA = 0.089 (90% CI 0.082-0.095), robust CFI = 0.845, robust TLI = 0.829 and SRMR = 0.063. Adding the five residual covariances supported by modification indices and conceptual overlap significantly improved fit (scaled $\Delta\chi^2 = 205.027$, $\Delta df = 5$, $P < 0.001$). The final model had scaled $\chi^2(313) = 625.587$, $\chi^2/df = 1.999$, robust RMSEA = 0.063 (90% CI 0.056-0.071), robust CFI = 0.921, robust TLI = 0.912 and SRMR = 0.056 (Table 3). The final solution contained no negative residual variances or standardised loadings greater than 1. Because the residual covariances were data-informed, the final model should be independently validated.

Caregiver burden had a negative path to health literacy (unstandardised estimate -0.100, robust SE 0.040, standardised estimate -0.189, $P = 0.013$), whereas self-efficacy had a positive path (unstandardised estimate 0.227, robust SE 0.053, standardised estimate 0.374, $P < 0.001$). The path from health anxiety to health literacy was not statistically significant (unstandardised estimate 0.029, robust SE 0.062, standardised estimate 0.037, $P = 0.644$) (Table 4; Figure 1). The model explained 19.6% of the variance in caregiver health literacy.

Discussion

Principal findings

In this single-centre sample of caregivers of patients with advanced cancer, education, caregiver burden and self-efficacy were independently associated with caregiver health literacy. The structural model showed a negative path from burden and a positive path from self-efficacy, whereas health anxiety did not retain an independent path after the other constructs were included. These findings extend previous cancer-caregiver studies by focusing on advanced disease and by examining health anxiety together with burden and self-efficacy in a Chinese caregiving context [5, 7].

Caregiver health literacy and sociodemographic context

The mean health-literacy score was similar to earlier Chinese work using the cancer-caregiver health-literacy scale [15]. However, the scale does not provide a diagnostic threshold that would justify labelling the sample as having adequate or inadequate health literacy. The score should therefore be interpreted descriptively and by considering variation across domains and caregiver groups.

Age, occupation, residence, education, relationship to the patient, income and self-rated health were associated with health literacy in univariate analyses. These patterns may reflect differences in access to education, digital information, health services and social support. Urban-rural disparities in health literacy have also been reported in China [16], while associations with education and access to information have been observed in other populations [17–20]. Because the present study did not directly measure mechanisms such as digital access or service availability, these explanations remain hypotheses for future research rather than demonstrated pathways.

Burden, self-efficacy and health anxiety

Higher caregiver burden may reduce the time, attention and emotional resources available for seeking, appraising and applying health information. Conversely, caregivers with stronger self-efficacy may be more confident in asking questions, practising care skills and acting on clinical advice. The observed paths are consistent with prior cancer-caregiver evidence linking health-literacy domains with burden and self-efficacy [5]. Nevertheless, the cross-sectional design cannot determine whether burden and self-efficacy shape health literacy, whether health literacy influences these experiences, or whether the associations are bidirectional.

Health anxiety was negatively correlated with health literacy at the bivariate level but was not independently associated in the regression or structural model. Health anxiety may overlap with burden or low self-efficacy, or its relationship with health literacy may be nonlinear or domain-specific. The findings do not support anxiety reduction alone as a means of improving health literacy, although anxious caregivers may still benefit from paced information, repeated explanation and psychological support.

Implications for nursing

Caregiver health literacy is relevant to nursing because caregivers often receive and act on information about medication, nutrition, symptom warning signs, adverse events and follow-up. Nurses should assess not only whether information has been delivered but also whether the caregiver can explain and apply it. Brief screening of comprehension, burden and confidence may help identify caregivers needing additional support.

Education may be stratified according to caregiver needs. Essential safety information should be prioritised and confirmed using teach-back, demonstration and return demonstration. Written or digital materials should use plain language and clear action steps [21]. For caregivers experiencing high burden,

education may need to be divided across encounters, shared with another family member and reinforced through telephone or community follow-up. These recommendations are consistent with the broader need for caregiver-health-literacy interventions that address individual, interpersonal and health-service factors [6].

Strengths and limitations

This study used a cancer-specific caregiver health-literacy measure and examined multiple caregiver-level constructs using regression and structural modelling. Several limitations should be considered. First, convenience sampling from one surgical department in one tertiary hospital limits representativeness and may under-represent caregivers in medical oncology, radiotherapy, palliative care or community settings. Second, the cross-sectional design precludes causal inference and temporal ordering. Third, self-report measures are subject to recall and social-desirability bias. Fourth, the data-informed residual covariances may have improved fit specifically in this sample and require external validation; two health-literacy domains also had comparatively low standardised loadings (0.353 and 0.339), indicating measurement weakness in these domains. Fifth, sparse categories, including only two caregivers reporting poor health, reduce the stability of some subgroup comparisons. Finally, patient cancer type, treatment status and dyadic patient-caregiver factors were not incorporated into the model. In addition, 17 patients each contributed two caregivers; the analysis treated caregivers as independent observations and did not explicitly model within-patient clustering, which may have modestly affected standard errors.

Conclusions

Education, caregiver burden and self-efficacy were associated with health literacy among caregivers of patients with advanced cancer. The findings support nursing approaches that combine clear, stratified education with assessment of caregiver burden and confidence. The path model is exploratory and requires validation in longitudinal, multicentre studies.

Abbreviations

CFI, comparative fit index; MLR, robust maximum likelihood estimation; RMSEA, root mean square error of approximation; SEM, structural equation modelling; SRMR, standardised root mean square residual; TLI, Tucker-Lewis index; VIF, variance inflation factor.

Declarations

Ethics approval and consent to participate

The Ethics Committee of Sir Run Run Shaw Hospital, Zhejiang University School of Medicine approved the study on 10 April 2024 (Approval No. Ethics 2024-Research-0238). Recruitment began after ethics approval and took place from April to July 2024. All participants provided written informed consent before questionnaire completion. The study was conducted in accordance with applicable institutional and ethical standards.

Consent for publication

Not applicable.

Availability of data and materials

The datasets used and analysed during the current study are available from the corresponding author on reasonable request, subject to ethics approval and participant privacy requirements.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

QW and HH conceived and designed the study. QW, CP, XZ and WW contributed to participant recruitment and data collection. QW performed the statistical analysis and drafted the manuscript. CP, XZ, WW and HH critically reviewed and revised the manuscript. All authors read and approved the final manuscript and agree to be accountable for the work.

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Authors' information

Not applicable.

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Tables

Table 1. Characteristics of participating caregivers (n = 280)

Variable	Category	n	%
Sex	Male	105	37.5
Sex	Female	175	62.5
Age	18-44 years	100	35.7
Age	45-59 years	88	31.4
Age	≥60 years	92	32.9
Marital status	Married	247	88.2
Marital status	Divorced/widowed/other	33	11.8
Religious belief	Yes	42	15.0
Religious belief	No	238	85.0
Occupation	Farmer	79	28.2
Occupation	Worker	47	16.8
Occupation	Other	154	55.0
Residence	Rural	123	43.9
Residence	Urban	157	56.1
Education	Primary school or below	42	15.0
Education	Junior middle school	82	29.3
Education	Senior high/technical secondary	67	23.9
Education	Junior college or above	89	31.8
Relationship	Spouse	135	48.2
Relationship	Child or parent	104	37.1
Relationship	Sibling or relative	19	6.8
Relationship	Other	22	7.9
Monthly income	<3000 yuan	102	36.4
Monthly income	3000-5000 yuan	79	28.2
Monthly income	>5000 yuan	99	35.4
Self-rated health	Good	215	76.8
Self-rated health	Fair	63	22.5
Self-rated health	Poor	2	0.7

Variable	Category	n	%
Chronic disease	Yes	58	20.7
Chronic disease	No	222	79.3
Caregiving duration	<1 year	165	58.9
Caregiving duration	1-3 years	69	24.6
Caregiving duration	>3 years	46	16.4

Percentages may not total 100 because of rounding.

Table 2. Multiple linear regression for total health literacy (n = 280)

Variable	B	SE	β	t	P	VIF
Constant	127.447	8.338	-	15.285	<0.001	-
Age	-1.347	1.567	-0.067	-0.859	0.391	2.208
Occupation: worker	-0.618	3.085	-0.014	-0.200	0.841	1.745
Occupation: other	0.278	2.605	0.008	0.107	0.915	2.205
Urban residence	4.209	2.352	0.126	1.789	0.075	1.789
Education	2.786	1.227	0.178	2.272	0.024	2.241
Relationship: child/parent	2.157	2.602	0.063	0.829	0.408	2.074
Relationship: sibling/relative	2.155	3.743	0.033	0.576	0.565	1.163
Relationship: other	1.258	3.846	0.020	0.327	0.744	1.405
Monthly income	-1.912	1.357	-0.097	-1.409	0.160	1.734
Self-rated health	-2.543	2.074	-0.068	-1.227	0.221	1.108
Caregiver burden	-0.196	0.063	-0.176	-3.107	0.002	1.170
Health anxiety	0.009	0.106	0.005	0.083	0.934	1.158
Self-efficacy	0.834	0.150	0.310	5.563	<0.001	1.126

B, unstandardised coefficient; β , standardised coefficient; SE, standard error; VIF, variance inflation factor. Nominal variables were represented by indicator variables.

Table 3. Fit indices for the base and final structural equation models

Model	Scaled χ^2	df	χ^2/df	Robust RMSEA (90% CI)	Robust CFI	Robust TLI	SRMR
Base	930.444	318	2.926	0.089 (0.082-0.095)	0.845	0.829	0.063
Final	625.587	313	1.999	0.063 (0.056-0.071)	0.921	0.912	0.056

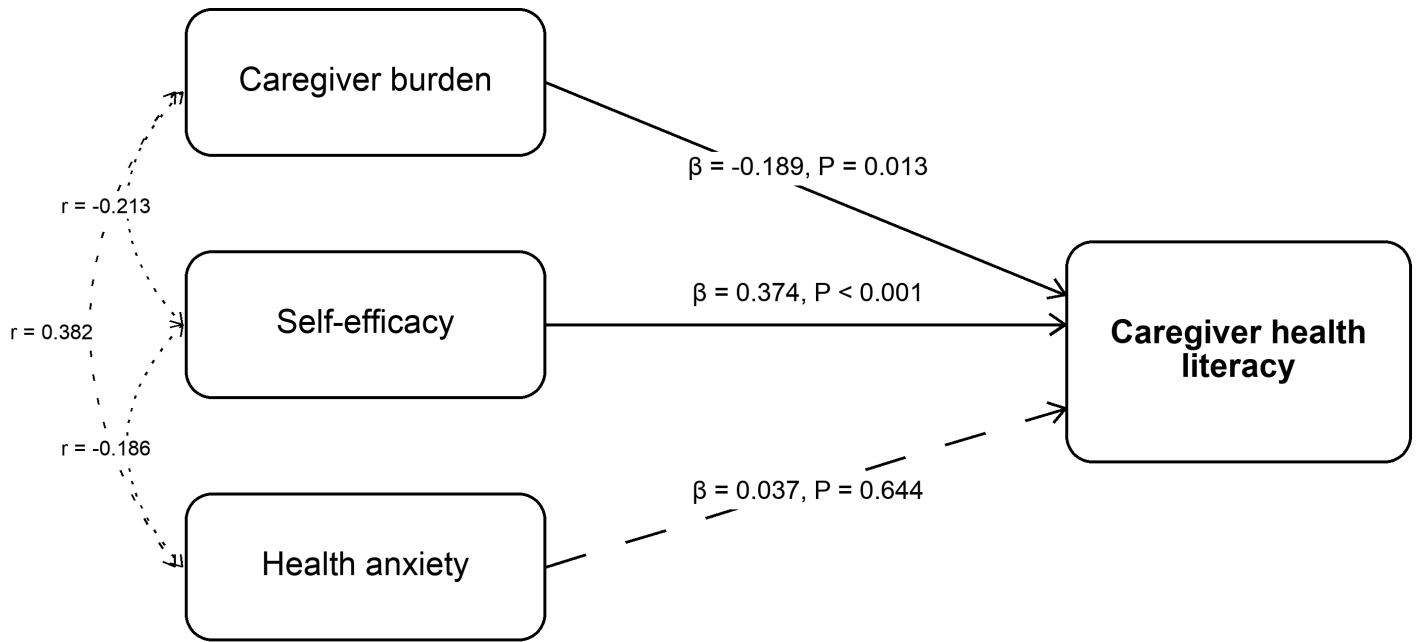
CFI, comparative fit index; RMSEA, root mean square error of approximation; SRMR, standardised root mean square residual; TLI, Tucker-Lewis index.

Table 4. Structural path coefficients

Path	B	β	Robust SE	z	P	95% CI for B
Caregiver burden → health literacy	-0.100	-0.189	0.040	-2.487	0.013	-0.179 to -0.021
Self-efficacy → health literacy	0.227	0.374	0.053	4.245	<0.001	0.122 to 0.331
Health anxiety → health literacy	0.029	0.037	0.062	0.462	0.644	-0.093 to 0.150

B, unstandardised coefficient; β , standardised coefficient; CI, confidence interval; SE, robust standard error; z, robust test statistic.

Figures



Solid paths: statistically significant; dashed path: not statistically significant; dotted double-headed arrows: correlations.

Figure 1

Structural paths associated with caregiver health literacy. Single-headed arrows show standardised regression paths and double-headed arrows show standardised correlations among the three exogenous constructs. Solid regression paths are statistically significant; the dashed regression path is not statistically significant. Measurement indicators and residual covariances are omitted for clarity.

Supplementary Files

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