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Clinical Sciences

What Makes Family Caregivers Happy During the First 2 Years Post Stroke?

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Background and Purpose—This study aimed to identify aspects of the caregiving situation contributing to family caregivers' psychological well-being.

Methods—Longitudinal cohort study with structured quantitative interviews 1, 3, 6, and 12 months post stroke. A subset of participants also completed surveys 18 and 24 months post stroke. Participants included individuals hospitalized for their first stroke and their family caregivers. Psychological well-being was assessed by the Positive Affect Scale.

Results—A total of 399 stroke survivor, caregiver dyads completed the 1-year follow-up and 80 dyads completed the second year of follow-up. Using mixed effects modeling for longitudinal data, caregivers reported more psychological well-being when they provided more assistance to stroke survivors who had fewer symptoms of depression, better cognitive functioning, and who had more severe strokes. In addition, caregivers who maintained participation in valued activities had more mastery, gained personally providing care, were in better physical health, were older, and were from Quebec reported more psychological well-being. Caregivers followed for a second year post stroke reported better psychological well-being when caring for stroke survivors with fewer symptoms of depression and more severe strokes and when the caregivers had a greater sense of mastery and gained more personally providing care.

Conclusions—Our findings contribute to the caregiver intervention development literature by identifying aspects of the caregiving situation that are associated with positive outcomes. Incorporating specific aspects, for example, strategies to enhance caregiver mastery into programs and services offered to caregivers may enhance their positive experiences with providing care and ultimately enhance the sustainability of the caregiving situation. **(*Stroke*. 2014;45:00-00.)**

Key Words: caregivers ■ cohort studies ■ longitudinal studies ■ psychological adaptation ■ stroke

The burden of providing care has received considerable attention in the stroke caregiving literature.[1–5] These results commonly suggest that providing care in the community to someone who has experienced a stroke can take a negative toll on informal caregivers' mental, physical, social, and financial well-being. At the same time, interventions to assist caregivers to stroke survivors have had little impact at reducing this burden.[6,7] More recent research recognizes that not all caregiving is a negative or stressful experience and some aspects can be beneficial and have a positive effect on caregiver psychological well-being.[8,9] Psychological well-being has been distinguished from emotional distress (eg, depression) and burden as it commonly denotes happiness, life satisfaction, and positive affect.[10–12] The general aging literature has identified potential contributors to caregiver psychological well-being, including personal growth, because of providing care,[13,14] caregiving satisfaction,[15] and positive feelings about caregiving.[16] Identifying aspects of the stroke caregiving situation that have a positive impact on caregiver psychological well-being may provide additional insight for intervention development, which traditionally focuses on alleviating negative aspects. In a time when formal community care is limited,[17] caregivers provide the majority of required care and assistance to stroke survivors residing in the community. Therefore, it is imperative to identify factors that influence the well-being of their caregivers.

In a recent literature review, Mackenzie and Greenwood[8] identified 3 quantitative and 6 qualitative studies examining positive experiences related to stroke caregiving. Findings across studies suggest caregivers report more positive outcomes when they see the stroke survivor making progress in their recovery, have improved relationships, feel appreciated, use positive coping strategies, and see improvements in their own self-esteem.[8] The review concluded by suggesting that more research on the positive outcomes of stroke caregiving was needed and that these studies should use longitudinal

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designs, include representative samples, and be guided by a theoretical framework.[8]

The use of a theoretical framework enhances our ability to make a comprehensive assessment of factors influencing caregiver well-being. Pearlin's Stress Process Model of family caregiving suggests providing care affects many aspects of caregivers lives, positively and negatively, and these outcomes are influenced by aspects of the caregiving situation and caregivers' abilities to draw on existing resources.[13,18] To facilitate our understanding of the factors contributing to caregiver psychological well-being, we adopted the Stress Process Model. Pearlin proposes that there are contextual factors (eg, sociodemographic characteristics of caregiver and stroke survivor, caregivers' own physical health), primary (eg, stroke severity, level of care provided) and secondary (eg, impact of providing care on caregivers' abilities to maintain participation in valued activities) stressors, and psychosocial resources (eg, mastery) that can affect caregiver outcomes.

Guided by Pearlin's model of family caregiving,[13] the objectives of this research were to (1) identify aspects of the caregiving situation that contribute to caregivers' psychological well-being and (2) examine changes in caregiver psychological well-being during the first year post stroke. The specific hypotheses were (1) caregivers who have more positive experiences providing care (eg, personal gain) and fewer negative experiences (eg, interference with participation in valued activities, stroke survivor with more severe stroke) will report more psychological well-being and (2) caregiver psychological well-being will increase during the first year post stroke.

Methodology

Research Design

The data for this study came from a longitudinal cohort study of individuals surviving their first stroke and their family caregivers from Toronto and London Ontario and Montreal Quebec.[19,20] Participants completed standardized measurement instruments by telephone 1, 3, 6, and 12 months post stroke (year-1 sample). A subset of participants from the Toronto site consented to be interviewed again 18 and 24 months post stroke (year-2 sample). Institutional ethics review boards approved this study. All participants provided written informed consent.

Participants

Members of the acute care clinical team identified stroke survivors and confirmed that this was their first hospitalization for either a hemorrhagic or ischemic stroke. Caregivers were identified as the person who was most likely to be a key provider of support and assistance when the stroke survivor was discharged home. Participants had to be able to speak and read English or French (Montreal).

Measurement Instruments

We obtained stroke survivors' and caregivers' sociodemographic information, including age, sex, primary daily activity (eg, caregiver, homemaker, working for pay, retired, etc), marital status, and income. Caregivers also provided information about their relationship to the stroke survivor (eg, spouse) and their living situation. Province of recruitment was considered because of the differences in healthcare systems. Review of hospital charts provided information about stroke severity, type (ischemic or hemorrhagic), hemisphere (left, right, or both), and location (hemispheric, cerebellum, or brain stem). The Canadian Neurological Scale[21] determined stroke severity with scores ranging from 1.5 to 11.5 and lower scores indicating more neurological damage.

Stroke survivors' physical disability, including indicators of overall strength, hand function, activities and instrumental activities of daily living, and mobility, was assessed by the physical domain of the Stroke Impact Scale.[22] A sum of z scores from the communication and memory subscales of the Stroke Impact Scale[22] and the Mini-Mental Status Exam[23] provided an estimate of cognitive impairment. The Charlson index provided an estimate of comorbidity.[24]

Caregivers rated the presence of behavioral and psychological symptoms in the stroke survivor using the 18-item Brain Impairment Behavior Inventory–Revised.[25] This scale assesses 4 domains (apathy, depression, memory/comprehension, and irritability) as identified by exploratory factor analysis.[25]

The amount of care provided with activities and instrumental activities of daily living and medical care was assessed by the 17-item Caregiver Assistance Scale.[26] We examined limitations in caregivers' abilities to participate in valued activities and interests because of providing care using the 14-item Caregiving Impact Scale (CIS).[26]

Caregiver mastery was assessed by Pearlin's 7-item measure.[27] Personal gain (ie, becoming aware of their inner strengths while providing care) was assessed by the 4-item Personal Gain Scale.[13] We determined the total number of community services received by the stroke survivor during the past month. Because of the large percentage who did not receive services (range, 35.8%–76.4%) across the 6 waves of assessment, this variable was dichotomized with zero indicating that the stroke survivor received no services and 1 indicating that they received ≥1 service.

Caregiver physical health was assessed by the physical health domain of the Medical Outcomes Study Short Form-36.[28] Caregiver psychological well-being was assessed by the 10-item Positive Affect Scale of the Positive and Negative Affect Schedule.[12]

Statistical Analyses

A series of individual growth curve models[29] were run using the SAS version 9.2 mixed-effect models procedure.[30] These models treated the intercept and time variables as random effects to represent individual differences in initial psychological well-being and rates of change during the first 2 years. The time variable was centered by subtracting 1 from each month of assessment, so the models' intercepts represented caregivers initial level of psychological well-being. The unconditional means model (A) provided an unadjusted estimate of the level of psychological well-being across all participants and all waves of data collection. The unconditional growth model (B) assessed unadjusted change in the dependent variable over time (hypothesis 2). Model C tested the full set of predictors (hypothesis 1). Removing estimates with the highest *P* value and then rerunning the analyses until all variables in the model made a significant ($P<0.10$) contribution to caregiver psychological well-being determined model D, the simplest model. Models A to D were conducted with the year-1 sample. Model E tested the simplest model (model D) in the year-2 subsample. Estimates are not standardized and indicate the amount of change in the dependent variable corresponding to a 1-point change in the independent variable. Goodness-of-fit indices (eg, deviance [−2 log likelihood], Akaike Information Criterion, and Bayesian Information Criterion) facilitated model comparison with lower scores indicating better fitting models.[29]

We tested the assumptions of this method, including ignorable missing data, every observation of the dependent variable having complete observations of the independent variables, linear change over time, linear relationships between the dependent variable and each independent variable, and residuals being normally distributed and homoscedastic. Missing independent variable data were replaced by the individual's closest available longitudinal datum.[31] The skew of some independent variables violated the models' assumptions. As a result, an additional model was run—full model with transformed independent variables. This model identified the same set of significant predictors as the untransformed full model (model C). Therefore, the untransformed model is presented to facilitate interpretation of the estimates. See online-only Data Supplement for a detailed description of the statistical analyses.

Sample Size

To use the full model approach with 21 independent variables and a minimum of 10 participants per variable, we needed a minimum sample of 210 stroke survivor/caregiver dyads.[32]

Table 1. Caregiver Sociodemographic Characteristics (n=399)

Characteristic	Year-1 Sample (n=399)	Year-2 Sample (n=80)
Age,* y	58.4 (14.55)	57.0 (14.23)
Women†	276 (69.2%)	50 (62.5%)
Relationship to stroke survivor†		
Spouse	278 (69.7%)	62 (77.5%)
Son/daughter/other	121 (30.3%)	18 (22.5%)
Marital status†		
Married/common-law	320 (80.2%)	66 (82.5%)
Single	48 (12%)	10 (12.5%)
Separated/widowed/divorced	28 (7.0%)	2 (2.6%)
Provided care previously†	163 (40.9%)	28 (35.0%)
Primary daily activity†		
Working for pay	136 (34.1%)	32 (40.0%)
Retired	88 (22.1%)	13 (16.3%)
Caregiver	26 (6.5%)	7 (8.8%)
Homemaker	70 (17.5%)	8 (10.0%)
Other	18 (4.5%)	3 (3.8%)
Live with stroke survivor†	341 (85.5%)	64 (80.0%)

Not all percentages add up to 100% because of missing data.
*Mean (SD) and †n (%).

Results

The analyses included 399 stroke survivor/caregiver dyads followed for 1 year and 80 dyads from the Toronto sample that reconsented to complete the 18- and 24-month assessments. The percentage of caregivers completing follow-up assessment ranged from 66% at 12 months to 86% at 1 month. Participants were from Toronto (n=171; 43%), London (n=69; 17%), and Montreal (n=159; 39%). Caregiver characteristics are presented in Table 1.

Stroke survivors' characteristics are presented in Table 2. Stroke survivors who had a caregiver participate in the study were representative of the full cohort except they were significantly younger, more likely to be married and men, and had a slightly more severe stroke (Table 2).

The results of the longitudinal analyses are presented in Table 3. The intercept in model A provides the overall mean psychological well-being score of the caregivers during the first year of data collection (35.9; $P<0.001$). Model B indicates

Table 2. Stroke Survivor Characteristics for Respondents and Nonrespondents (n=678)

Characteristic	Respondents (n=399)*	Nonrespondents (n=279)*	*P* Value
Age, y	68.2 (56.79–77.04)	71.4 (58.97–79.84)	0.051
Men	235 (59.0%)	137 (49.1%)	0.010
Married	268 (71.3%)	95 (36.0%)	0.000
Working	88 (24.7%)	55 (21.7%)	0.378
Province			0.765
Ontario	240 (60.2%)	171 (63.1%)	
Quebec	159 (39.8%)	108 (38.7%)	
CNS	9.0 (7.0–10.5)	9.25 (7.5–10.5)	0.050
Barthel Index	80 (55–100)	85 (58.75–100)	0.133
No. of comorbid conditions	2 (1–4)	3 (1–4)	0.278
Charlson Index	1 (0–2)	1 (0–2)	0.489
SIS-physical domain	70.5 (40.17–87.5)	71.4 (43.75–88.84)	0.482
MMSE	21 (19–22)	21 (19–22)	0.238
Hospital stay, d	11 (6–19)	11 (6–18)	0.210
Home care services	2 (0–6)	1 (0–4)	0.047
Side of cerebral lesion			0.855
Left	173 (43.6%)	120 (43.2%)	
Right	194 (48.9%)	131 (47.1%)	
Both	18 (4.5%)	18 (6.5%)	
Stroke type			0.153
Ischemic	354 (89.2%)	257 (92.4%)	
Hemorrhagic	43 (10.8%)	21 (7.6%)	
Stroke location			0.905
Hemispheric	329 (82.9%)	233 (84.1%)	
Cerebellum	44 (11.1%)	29 (10.5%)	
Brain stem	24 (6.0%)	15 (5.4%)	

CNS indicates Canadian Neurological Scale; Charlson, the Charlson Comorbidity Index; Comorbidity, the number of comorbid conditions; MMSE, Mini-Mental Status Examination telephone version; and SIS-physical domain, Stroke Impact Scale Physical Health Domain Score.

*Data from 1-month patient interview; number (percentage) or median (interquartile range).

no significant change in psychological well-being during the first year post stroke (−0.01; $P>0.05$). Quadratic change was also tested to identify any nonlinear change but was nonsignificant (results not shown).

The full model (model C) suggests that more psychological well-being was associated with caregivers providing higher levels of assistance (0.06; $P<0.001$), experiencing less interference with valued activities (−0.05; $P<0.01$), being in better physical health (0.21; $P<0.001$), gaining more as a result of providing care (0.35; $P<0.001$), having greater sense of control over life (mastery 0.62; $P<0.001$), being older (0.07; $P<0.05$), and caring for a stroke survivor who has less cognitive impairment (0.31; $P<0.01$), more severe stroke (Canadian Neurological Scale, −0.35; $P<0.01$), and less depression (−0.8; $P<0.05$). Stroke survivor physical disability was not significantly associated with caregiver psychological well-being (0.02; $P>0.05$). Changes in caregiver psychological well-being over time remained nonsignificant when considering all the variables in the model (−0.05; $P>0.05$). These findings are consistent with the simplest model (model D). Rerunning the simplest model in the sample of caregivers who were followed for a second year post stroke, higher psychological well-being was associated with stroke survivors having fewer symptoms of depression (−1.89; $P<0.05$) and more severe strokes (−1.04; $P<0.01$) and caregivers having greater sense of control over life (mastery, 0.47; $P<0.001$) and gaining more personally as a result of providing care (0.49; $P<0.01$; model E).

Discussion

In this sample of family caregivers to individuals who had been hospitalized for their first stroke and using Pearlin's Stress Process Model as a guide, we were able to consider patient and caregiver factors that influence caregiver psychological well-being. Our caregivers reported more psychological well-being when stroke survivors exhibited fewer depressive symptoms, had better cognitive functioning, and had more severe strokes. They also reported more psychological well-being when they provided more assistance to the stroke survivor, maintained participation in valued activities, were in better physical health, were older, were able to gain personally as a result of providing care, and had higher levels of mastery or control over their lives. Caregiver psychological well-being was stable during the 2-year follow-up period. These findings begin to characterize factors that constitute a positive caregiving situation.

The finding that caregiver psychological well-being was stable during the follow-up period is a new contribution to

Table 3. Summary Mixed-Effect Models for Psychological Well-Being

Fixed Effects Initial Status, π_{0i}	Model A	Model B	Model C	Model D	Model E
Intercept	35.9 (0.36)*		10.11 (3.42)†	9.57 (3.0)†	30.6 (7.86)*
Time		−0.01 (0.04)	−0.05 (0.04)	−0.06 (0.04)	−0.05 (0.08)
Province			−1.36 (0.65)‡	−1.43 (0.61)‡	
Caregiver age§			0.07 (0.03)‡	0.06 (0.02)†	0.05 (0.06)
Caregiver female§			−0.28 (0.87)		
Working§			0.43 (0.56)		
Caring for spouse§			−1.06 (0.86)		
Caregiving Impact Scale§			−0.05 (0.02)†	−0.05 (0.01)†	−0.06 (0.04)‖
Caregiver Assistance Scale§			0.06 (0.01)*	0.06 (0.01)*	0.01 (0.03)
Mastery§			0.62 (0.07)*	0.63 (0.07)*	0.47 (0.13)*
Caregiver physical health§			0.21 (0.03)*	0.22 (0.03)*	0.03 (0.07)
Personal gain§			0.35 (0.07)*	0.35 (0.07)*	0.49 (0.15)†
Stroke survivor age¶			−0.01 (0.03)		
Stroke survivor female¶			−0.52 (0.83)		
BPS depression¶			−0.80 (0.34)‡	−1.00 (0.29)*	−1.89 (0.79)‡
BPS irritability¶			−0.20 (0.30)		
BPS apathy¶			−0.24 (0.30)		
BPS memory¶			−0.06 (0.40)		
SIS-physical component¶			0.02 (0.01)	0.02 (01)	0.01 (0.03)
Cognitive composite score¶			0.31 (0.12)†	0.33 (0.11)†	0.27 (0.30)
CNS¶			−0.35 (0.12)†	−0.35 (0.11)	−1.04 (0.33)†
Charlson Index¶			−0.22 (0.19)		
Community service¶			0.08 (0.37)		

Estimate (SE). Province: 0, Quebec and 1, Ontario. Community service: 0, no services received; 1, at least 1 service received. Model A, unconditional means model; model B, unconditional growth model; model C, year-1 sample full model; model D, year-1 sample simplest model; and model E, repeat of model D with year-2 sample. BPS indicates behavioral and psychological symptoms; CNS, Canadian Neurological Scale; and SIS, Stroke Impact Scale.

*$P<0.001$; †$P<0.01$; ‡$P<0.05$; §caregiver provided this information; ‖$P<0.1$; and ¶stroke survivor provided this information.

the stroke caregiving literature. Only 1 quantitative study has examined positive changes in stroke caregiving over time and this exploratory 4 case study design suggested increases in positive caregiving experiences during a 6-week follow-up period.[33] Our findings suggest that on average, across a larger sample, psychological well-being in family caregivers is stable over time. In contrast, negative caregiver outcomes, for example, depression, have been seen to decrease over time.[19] Our findings are consistent with the authors of the Positive and Negative Affect Scales who have observed decreases in negative affect and no change in positive affect during a 6- to 7-year period in undergraduate students followed up over time.[34] In addition, caregiver psychological well-being scores in our sample were consistent with reported population norms.[35]

Findings related to characteristics of the patient suggest that caregivers struggle more with the emotional and cognitive consequences of stroke than the physical limitations, and that milder strokes in patients may be related to poorer psychological well-being of caregivers. These findings are consistent with previous research that suggests that cognitive disability and depression symptoms in the stroke survivor are associated with caregivers' symptoms of depression.[19] In research with survivors of mild stroke and their spousal caregivers, although physical functioning was either good or improving, depression and marital functioning worsened during the year post stroke, suggesting that mild strokes can still have a negative impact.[36] Qualitative research with mild stroke survivors and spousal caregivers also suggests adjustments to lifestyle are made and caregivers feel the need to be vigilant.[37] As a result, caregivers may require more guidance managing the emotional and cognitive consequences of stroke and more guidance on managing and adjusting to life with a mild stroke than is routinely provided by the healthcare system.[38]

Our findings also suggest that when caregivers gain personally as a result of providing care have high levels of mastery, are in good physical health, and provide higher levels of assistance; they report better psychological well-being. These findings begin to delineate the characteristics of a positive caregiving situation. Family caregivers may derive personal happiness and become aware of their inner strengths (personal gain) when they are actively involved in the care of their family member. This is more likely to occur when caregivers are in good physical health and have higher levels of mastery and are caring for stroke survivors with less cognitive impairment and depressive symptoms. Previous qualitative and quantitative research suggest that caregivers feeling needed and appreciated, and gaining a sense of fulfillment and a positive attitude are positive outcomes associated with providing care.[39] This is consistent with our observation that gaining personally as a result of providing care was associated with psychological well-being. Previous studies have also identified strengthened relationships as a positive outcome of providing care.[39] We did not assess relationship quality in our study, but this aspect and its relationship to psychological well-being warrant further investigation.

This study had some limitations. We recruited a sample of first stroke survivors who were able to communicate and cognitively able to consent to participate in the study to learn from their family's first experience caring for someone post stroke and, as a result, our survivors had mild-to-moderate stroke severity. It would be informative to explore positive experiences with providing care to individuals who have had more debilitating strokes to see whether our set of significant predictors remains the same, but this is not possible within our study. Our second-year follow-up included a small select sample from Toronto limiting the generalizability of our 2-year findings. A variety of individuals across research sites recruited stroke survivors and their caregivers into the study when patients were admitted to acute care. We did not have standardized processes for recording recruitment information and, therefore, we are not able to comment reliably on the representativeness of this sample. We did not collect any data on the caregivers' precaregiving psychological state so we are not able to conclude that caregiving results in positive outcomes as it may be that caregivers predisposed to a positive psychological state may be more likely to take on the caregiving role. This study could also have benefited from collecting qualitative data from a subset of the participants to obtain a more in-depth understanding of their positive experiences with providing care and their impact on psychological well-being.

In summary, our research with a large sample of stroke survivor/caregiver dyads followed for the first 2 years post stroke has identified some key aspects of the stroke caregiving situation that are associated with positive outcomes. These findings can begin to characterize good caregiving situations that may inform intervention development so as to assist caregivers to derive benefits from providing care and, ultimately, enhance the sustainability of the caregiving situation.

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Disclosures

None.

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SUPPLEMENTAL MATERIAL

Individual Growth Curve (IGC) Modeling was used to determine the pattern of change in informal caregiver psychological wellbeing during the first two years post stroke and identify aspects of the caregiving situation associated with psychological wellbeing. IGC modeling facilitates examination of the relationship between variables within individuals as opposed to across individuals and has many advantages over traditional methods of longitudinal data analysis [1, 2].

Prior to conducting the analyses a number of preliminary steps were performed. First, a basic assumption of IGC modeling is that missing assessments of the dependent variable are ignorable (i.e., missing completely at random or missing at random). Second, IGC modeling requires complete information on all the independent variables for each measurement of the dependent variable [3]. As a result, the availability of independent variables was determined for each observation of the dependent variable. With only a small amount of missing data (<5%) we used last-observation-carried-forward to replace missing data [4]. Third, IGC modeling assumes continuous variables are normally distributed. The distributions of all continuous variables were examined and transformed to improve the distribution when necessary. IGC analyses were conducted with and without the transformed data to determine which data provided a better fit for the models assumptions. Fourth, IGC modeling assumes measurement of variables is constant over time [2]. Therefore, the internal consistency of each measure was computed for each wave to ensure the internal consistency was approximately equal across waves.

Fourth, centring the dependent variable is often recommended in longitudinal analysis to enhance the interpretability of the intercept. In this instance it represented the starting level of psychological wellbeing for caregivers before they assume/resume their care-giving role post stroke. Time was coded as 0, 2, 5, 11, 17, and 23 to correspond to the 1, 3, 6, 12, 18, and 24-month post-stroke assessments.

Fifth, correlations of all the independent and dependent variables were computed for each wave of data collection to determine the bivariate relationships between variables. This procedure identifies any relationships between the independent variables that may indicate multi-collinearity. When bivariate correlations over .80 [5] or .90 [6] are observed, combining those scales into one indicator should be considered. Multi-collinearity may make interpretation of model estimates difficult since, when multi-collinearity is present variance estimates can become inflated, resulting in type II error (i.e., failing to reject the null hypothesis when it is false [5]).

IGC analyses consist of two model levels (see Figure 1 for examples). The level-one (level-1) model describes how individuals change over time and identifies factors that are associated with this change. The effects of time-varying covariates (i.e., variables that are measured at each occasion) are tested in the level-1 model. The level-two (level-2) model facilitates examination of inter-individual differences in starting point (i.e., intercept) and/or rate of change (i.e., slope). Level-2 predictors are time invariant including characteristics of the individual (e.g., sex). These two models are combined into a composite model to facilitate analyses with most statistical analysis programs (e.g., SAS, SPSS).

Level-1 Model

$$Y_{ij} = \pi_{0i} + \pi_{1i}TIME_{ij} + \varepsilon_{ij}$$

Level-2 Models

$$\pi_{0i} = \gamma_{00} + \gamma_{01}SEX_i + \zeta_{0i}$$

$$\pi_{1i} = \gamma_{01} + \gamma_{11}SEX_i + \zeta_{1i}$$

Composite Model

$$Y_{ij} = \underbrace{\left[\gamma_{00} + \gamma_{10}TIME_{ij} + \gamma_{01}SEX_i + \gamma_{11}(SEX_i XTIME_{IJ})\right]}_{\text{Fixed Effects}} + \underbrace{\left[\zeta_{0i} + \zeta_{1i}TIME_{ij} + \varepsilon_{ij}\right]}_{\text{Random Effects}}$$

i = individual
j = occasion of measurement
Yij = outcome

Fixed Effects

γ_{00} = Average true initial status

γ_{10} = Average true rate of change

γ_{01} = Predictor variable (e.g., sex)

γ_{11} = Predictor variable (e.g., sex by time interaction)

Random Effects

ε_{ij} = Average scatter of each individuals' observed outcome around true change trajectory

ζ_{0i} =Deviation between each individual's intercept and population intercept

ζ_{1i} = Deviation between each individual's rate of change and population rate of change

Variance Components

σ_{ε}^{2} = Scatter of observed data around hypothesized change trajectory

σ_{0}^{2} = Population residual variation in true initial status

σ_{1}^{2} = Population residual variation in true rate of change

σ_{01} = Covariance between true intercept and true slope across all individuals

Figure I. Components and their Definitions for Individual Growth Curve Models.

The mixed effects model contains fixed and random effects. In fixed effects, the relationship between a person-specific predictor with the dependent variable is constant across population members. For example, experiencing more lifestyle interference due to the care-giving role will be associated with lower levels of psychological wellbeing consistently across caregivers. Random effects allow the effect of a variable to vary across individuals in the population. For example, informal caregivers will have different initial levels of psychological wellbeing and, therefore, the intercept is modelled as a random effect.

The assumptions underlying the statistical models of IGC are specific to the two levels and to the fixed and random effects. Testing the assumptions ensures that the statistical methods are appropriate for this data and that model estimates can be safely interpreted. The assumptions include the functional form including shape of change (i.e., linear) and the relationship between variables is linear [2]. If we assume and model a linear change over time (level-1) we can test this assumption by plotting growth curves for each participant. By visual inspection, the data points should appear to follow the fitted line. For level-2, a scatter plot of each independent variable with the dependent variable should suggest a straight line. For dichotomous predictors (e.g., sex), the linear model is assumed [2].

Two additional assumptions are that the residuals are normally distributed and homoscedastic [2]. Normality is assessed by visual inspection of the raw residuals, one for level-1 and two for level-2 (intercept and slope). Each residual plotted against a normal score should form straight lines. In addition, no discernable pattern should be seen when residuals are plotted against participant identification numbers and 95% of cases should fall within two standard deviations and none should exceed three standard deviations. Homoscedasticity, the variance is constant over time, is tested by plotting the raw residuals against the predictors. The homoscedasticity assumption is met if the residual variability is approximately equal at every predictor value; specifically, there should be no discernable pattern.

Different methods of estimation are used in IGC modeling. Traditional ordinary least squares methods of estimation used in regression analyses require residuals to be independent and homoscedastic. These assumptions are violated because of two common characteristics of repeated measures data; autocorrelation and heteroscedasticity. Autocorrelation occurs when the unexplained portion of an individual's outcome at one assessment period is correlated with the unexplained portion at another assessment period [2]. This is usually due to omitted predictors because their effects may be present identically in each residual over time; an individual's residuals may become linked across occasions. For example, caring for young children may have a consistent and stable influence on mental health. When excluded from caregiver research, its effects may be constantly observed in the residuals over time and, therefore, contribute to autocorrelation.

Heteroscedasticity occurs when the unexplained portion of each person's outcome has unequal variances across occasions [2]. This is also commonly due to omitted predictors. For example, one source may be the omission of social support. It may have a larger influence earlier on in the care trajectory when social support is more readily available. Since social support to caregivers has a tendency to dissipate over time [7], its presence in the residuals may also decrease.

Since OLS methods of estimation are not appropriate for repeated assessment data, there are primarily two methods of estimation that can be used: maximum likelihood and generalized least squares. Maximum likelihood (ML) is usually the preferred method of estimation since it stems from normal theory [2]. The estimates under this approach are guesses for the values of the population parameters that maximize the probability of observing the sample data [2]. These estimates become more precise as the sample size increases. The likelihood and log-likelihood functions estimate model fit. The disadvantage of this full ML procedure is that it ignores uncertainty about the fixed effects when estimating the variance components by failing to allow some degrees of freedom for the fixed effects. This over estimates the degrees of freedom and under estimates of the variance components [2]. Restricted ML overcomes this problem by adjusting for the fixed effects degrees of freedom but the disadvantage of the restricted ML approach is that the goodness-of-fit statistics only allow testing hypotheses or comparing models with respect to the variance components not the fixed effects.

The generalized least squares (GLS) method is an extension of ordinary least squares. The estimates produced under this approach minimize the distance (i.e., residuals) between the observed data and the estimates of the population parameters. Iterative GLS is an extension of this approach that continues to re-fit the GLS model until the fit no longer improves and the model converges. The results of the ML and GLS methods are the same when the normality assumptions of ML are met. Specifically, the GLS approach can be used when the ML assumption that the residuals are normally distributed is violated. For this study, full ML methods will be used unless there are serious violations of the assumptions, where other methods will be tested as appropriate.

In addition to the methods of estimation, the structure of the covariance matrix is also of importance. Covariance structures are necessary because assessments of each individual are assumed to be correlated over time [3]. The most commonly used and least restrictive covariance structure is the unstructured covariance [3]. It is also a good choice when the number of assessments is small. As the amount of missing data increases, stable estimates may be more difficult to achieve and more restrictive structures may need to be used (e.g., Toplitz). These analyses used unstructured covariance since there were only four waves of data.

Fitting models using IGC analysis commonly occurs in stages. The first stage, the unconditional means model, computes the null model with no predictors. We examine the variance components to determine if 1) there is variability within individuals (i.e., their scores change over time) and 2) there is inter-individual variability (i.e., there is variability between individuals suggesting the need for level-2 predictors). Variability exists if the variance components are significantly different from zero. When this occurs, more predictors are added to the model to attempt to explain this variability.

The second stage, the unconditional growth model, adds time as a predictor. This model tells us if there is change over time in the dependent variable. The level-1 variance component indicates scatter of each individuals' data around their linear change trajectory and level-2 variance components indicate variability across individuals in initial status and rate of change. Again, when they are significantly different from zero, this suggests adding additional predictors to try to explain more of the variability.

Often many different models are tested to determine which model provides the best fit to the available data. The log-likelihood, Akaike Information Criteria (AIC), and Bayesian Information Criteria (BIC) are indicators of model fit produced by most statistical programs [2]. Sample size and the number of parameters in the model influence indicators of model fit. To determine which model provides a better fit, these statistics can be compared across models. The likelihood ratio test can be used to compare the –2log likelihood's of two models if two criteria are satisfied: 1) each model uses identical data and 2) one model must be nested within the other (i.e., one model tests a subset of the parameters in a larger model). The likelihood ratio test is calculated by computing the difference between the two model's –2log likelihood estimates and tested as a chi-square statistic with the degrees of freedom equal to the difference in the number of parameters between the two models.

The AIC takes into consideration the number of parameters in the model so these values are directly comparable across models with the lower AIC indicating better fit. The BIC is similar to the AIC in that it controls for the number of parameters in the model but it also controls for the sample size. Specifically, with larger sample sizes you want a larger improvement before you prefer a more complex model. The advantage of using either the AIC or BIC is that they allow comparison of non-nested models, i.e., models with different sets of predictors.

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