

Measuring positive caregiving experiences in family caregivers of nursing home residents: a comparison of the Positive Experiences Scale, Gain in Alzheimer Care INstrument, and Positive Aspects of Caregiving questionnaire

Smaling, H.J.A.; Joling, K.J.; Achterberg, W.P.; Francke, A.L.; Steen, J.T. van der

Citation

Smaling, H. J. A., Joling, K. J., Achterberg, W. P., Francke, A. L., & Steen, J. T. van der. (2021). Measuring positive caregiving experiences in family caregivers of nursing home residents: a comparison of the Positive Experiences Scale, Gain in Alzheimer Care INstrument, and Positive Aspects of Caregiving questionnaire. *Geriatrics And Gerontology International*, 21(8), 636-643. doi:10.1111/ggi.14210

Version: Publisher's Version

License: <u>Creative Commons CC BY-NC-ND 4.0 license</u>

Downloaded from: https://hdl.handle.net/1887/3220652

Note: To cite this publication please use the final published version (if applicable).

DOI: 10.1111/ggi.14210

ORIGINAL ARTICLE

EPIDEMIOLOGY, CLINICAL PRACTICE AND HEALTH

Measuring positive caregiving experiences in family caregivers of nursing home residents: A comparison of the Positive Experiences Scale, Gain in Alzheimer Care INstrument, and Positive Aspects of Caregiving questionnaire

Hanneke JA Smaling,^{1,2} • Karlijn J Joling,³ Wilco P Achterberg,¹ Anneke L Francke^{2,4} and Jenny T van der Steen¹

¹Department of Public Health and Primary Care, Leiden University Medical Center, Leiden, the Netherlands

²Department of Public and Occupational Health, Amsterdam Public Health Research Institute, Amsterdam UMC, VU University Medical Center, Amsterdam, the Netherlands

³Department of General Practice and Elderly Care Medicine, Amsterdam Public Health Research Institute, Amsterdam UMC, Vrije Universiteit Amsterdam, Amsterdam, the Netherlands ⁴Netherlands Institute for Health Services Research (NIVEL), Utrecht, the Netherlands

Correspondence

Dr. Hanneke JA Smaling,
Department of Public Health and
Primary Care, Leiden University
Medical Center, Hippocratespad
21, Gebouw 3, Postal zone V0-P,
P.O. Box 9600, 2300 RC Leiden,
the Netherlands.

Email: h.j.a.smaling@lumc.nl

Received: 19 September 2020 Revised: 10 May 2021 Accepted: 23 May 2021 **Aim:** To compare the Positive Experiences Scale (PES), Gain in Alzheimer Care INstrument (GAIN) and Positive Aspects of Caregiving (PAC) in assessing positive caregiving experiences among caregivers of nursing home residents with dementia, and to explore which caregiver and care recipient characteristics relate to positive caregiving experiences.

Methods: A total of 63 caregivers (mean age 59.2 years; SD 11.8) of nursing home residents with dementia from four Dutch nursing homes participated in this cross-sectional observational study. Internal consistency, convergent validity and user-friendliness (i.e. perception of item relevance and comprehensibility, ease of use, missing items, and user preference) were examined using Cronbach's alpha's, correlation coefficients and descriptive statistics, respectively.

Results: The Cronbach's alpha for the GAIN, PAC and PES was 0.90, 0.94 and 0.68, respectively. The sum score of the PES showed a ceiling effect. Convergent validity was confirmed for all three instruments. The PES had the least missing data (mean number of missing items 0.2, SD 0.5) and was preferred by 40% of the caregivers, followed by the GAIN (mean number of missing items 0.6, SD 1.7, preferred by 11%). Positive caregiving experiences were negatively associated with educational level (range -0.28 to -0.35). Only the PES correlated positively with caregiver age (r = 0.25).

Conclusions: All three questionnaires can be used to assess positive caregiving experiences, but the GAIN might be the most suitable questionnaire for caregivers of nursing home residents with dementia. Further research is necessary to examine generalizability of the findings. **Geriatr Gerontol Int 2021; 21: 636–643**.

Keywords: caregivers, dementia, internal consistency, nursing homes, positive caregiving experiences.

Introduction

A substantial part of the care for people with dementia is provided by family caregivers.¹ Family caregivers of people with dementia, on average, provide care for more years than caregivers of care recipients with other diseases, and continue to assist the person with dementia after nursing home admission.² Caregiver burden does not necessarily decrease after nursing home admission.³

However, caregivers also report positive aspects of caregiving, such as deriving a sense of personal accomplishment and gratification, experiencing personal growth, improved relationships, and gaining a renewed perspective in life.⁴⁻⁶ Positive caregiving experiences

(e.g. perceived benefits and gains) can increase caregivers' well-being,⁷ and relate to lower caregiver burden and better mental health.^{8–10} Understanding factors associated with positive caregiving experiences can help optimize interventions for caregivers.

To this end, a user-friendly, valid and reliable instrument to assess positive caregiving experiences is essential. However, psychometric properties and user-friendliness of the available instruments are scarcely reported.^{7,11} Also, the instruments have been used primarily among caregivers of community-dwelling people with dementia. ^{10,12–14}

Most caregivers want to continue an active role in the care for their relative after nursing home admission. ¹⁵ As caregiving experiences and responsibilities might differ in the nursing home where family can visit and help to provide care, but are not the primary care providers, it is important to also examine positive caregiving experiences in the nursing home setting.

The present study examined whether the Positive Experiences Scale (PES), ¹⁴ Gain in Alzheimer Care INstrument (GAIN) ¹⁰ and Positive Aspects of Caregiving measure (PAC) ¹² can be used to measure positive caregiving experiences among family caregivers of nursing home residents with dementia. The primary aim was to compare the internal consistency, convergent validity and userfriendliness (i.e. perception of item relevance and comprehensibility, ease of use, missing items, and user preference) of the questionnaires. A secondary aim was to explore if caregiver and care recipient characteristics related to positive caregiving experiences.

Methods

In the present cross-sectional observational study, data were collected in four Dutch nursing homes between June and August 2015. The study was reviewed by the Medical Ethics Review Committee of the VU University Medical Center as part of the Namaste study (trial registration: NTR5570)¹⁶ and deemed exempt from the Medical Research Involving Human Subjects Act (protocol number: 2015.191). The Namaste study¹⁶ consists of three substudies: (i) the current study; (ii) a cluster randomized controlled trial to examine the effects of the Namaste Care Family program on quality of life of nursing home residents with dementia and on caregiving experiences; and (iii) a pilot study to examine the feasibility of the program for community-dwelling people with dementia. There is no duplication between the data reported in the present study and data reported in the cluster randomized controlled trial or community pilot study.

Written permission to reproduce the items was obtained from the first authors of the PES¹⁴ and GAIN.¹⁰ For the PAC,¹² preapproved permission was received from Sage Publishing; they allow republishing of no more than a total of 200 words or 10% of the article, whichever is less, from a single journal article within a new publication.¹⁷

Participants

A convenience sample of nursing homes with a psychogeriatric long-stay department for dementia was recruited from the researchers' network. Dutch nursing homes provide 24-h oversight by multidisciplinary teams in addition to room and board, for persons who require assistance with activities of daily living and who often have complex health needs. ¹⁸ In the Netherlands, the team is led by certified elderly care physicians.

The inclusion criterion for caregivers was having a relative diagnosed with dementia living in a long-stay psychogeriatric unit. The nursing homes sent eligible caregivers an invitation to participate in the study, a participant information letter, a consent form and a booklet with questionnaires. Interested caregivers were asked to fill in the consent form and the booklet, and return these to the researchers.

Instruments

The forward-backward translation technique was used to translate the GAIN and PAC. ¹⁹ First, two researchers independently translated the English items into Dutch. Second, they compared their translations and came to a consensus. Third, the back-translation was carried out by a professional, independent translator. Finally, the translation was reviewed by the researchers who had translated into Dutch and discussed with the principal investigator. The professional translator and original authors were consulted for any remaining questions.

The Dutch PES measures positive aspects of caregiving for persons with any chronic disease. Height items are scored on a 3-point Likert scale from "agree" (3) to "disagree" (1). Summed scores range from 8 to 24, with higher scores indicating more positive caregiving experiences. Previous work in the Netherlands showed psychometric properties were satisfactory. Although de Boer et al. advised using the six-item version for caregivers of people with dementia (exclude items "I get a lot of appreciation for the help I provide" and "Helping has made my relationship with my family and friends closer"), we used the eight-item version to asses if these items were also less suitable in the case of caring for people with dementia in long-term care.

The GAIN assesses caregivers' gains in dementia caregiving. ¹⁰ The 10 items are scored on a 5-point Likert scale from "disagree a lot" (0) to "agree a lot" (4). Summed scores range from 0 to 40, with higher scores indicating more caregiving gains. The GAIN was found to be psychometrically reliable and valid among caregivers of community-dwelling people with dementia from Singapore. ^{10,13}

The PAC is a nine-item questionnaire, rated on a 5-point Likert scale ranging from 1 (disagree a lot) to 5 (agree a lot). ¹² It measures positive aspects of caregiving. The items comprise two dimensions: (i) self-affirmation; and (ii) outlook on life. Items are summed to create a sum score ranging from 1 to 45, with higher scores indicating more positive caregiving experiences. The PAC was found psychometrically sound in a sample of caregivers living with the person with dementia. ¹²

The visual analog scale (VAS) is a single item that we used to assess self-rated positive caregiving experiences. A common approach for measuring convergent validity is the computation of the correlation between the single-item measure (VAS) and its multi-item counterpart (PES, GAIN, PAC).²⁰ The caregiver was asked to indicate to what extent they experienced positive caregiving experiences, with 0 anchored at "no positive caregiving experiences" and 10 "only positive caregiving experiences".

The Family Visit Scale for Dementia (FAVS-D) measures the quality of family visits. 21 Caregivers rate 14 items about the last visit to the resident on a 5-point scale. To assess convergent validity, an adapted connection and experiences score ($\alpha=0.73$) was created based on the items that related to the connection between the caregiver and resident or the experience of the visit more generally (items 1–4, 7, 14). The possible range is -12 to 12, with higher scores indicating a better connection and experience. We excluded the other items that evaluated staff or facility.

The caregivers reported age, sex, educational level of themselves and the care recipient, relationship to the care recipient and how long the care recipient resided in the nursing home. The severity of the dementia was measured with the seven-item Bedford Alzheimer Nursing Severity-Scale (BANS-S) that was

completed by nursing home staff.²² Total scores range from 7 to 28, with \ge 17 indicating severe dementia.²³ In the present sample, Cronbach's α was 0.82.

Procedure

Participants filled in a paper booklet, consisting of two parts. The first part started with general questions to assess caregiver and care recipient characteristics, followed by the PES, GAIN, PAC and VAS. Next, caregivers were instructed to indicate which items of the questionnaires they thought of as "not relevant" and "unclear" by checking the corresponding boxes after each item. They were asked to comment in open text fields about whether they missed items or had additional comments about the questionnaires, and to choose which questionnaire they preferred. No preference was also a valid response option. Plus, they completed the FAVS-D, which was included in the second part of the booklet. This second part contained newly translated instruments that had been validated elsewhere. We report on the first part in the present study.

Statistical analysis

Internal consistency was calculated using Cronbach's α . Cronbach's α -values ranging from 0.70 to 0.95 are generally considered acceptable. The missing completely at random test was used to investigate whether the missing were at random. Missing values on individual items of (sub)scales were imputed by the participant mean for all cases with a minimum of 75% complete data. Ceiling or floor effects are defined as >15% of respondents rating the highest or lowest possible score, respectively.

Convergent validity was assessed using correlation coefficients between the PES, GAIN, PAC, VAS, and FAVS-D connection and experiences score. Strong correlations (>0.70) were expected among the PES, GAIN and PAC, and between the three questionnaires and VAS, and moderate correlations (0.40–0.70) with the FAVS-D connection and experiences score.

Descriptive statistics were given for the PES, GAIN and PAC to assess the user-friendliness. Correlation coefficients were calculated between positive caregiving experiences and caregiver and care recipient characteristics.

A minimum sample size of 50 is required for adequate power for validity and reliability studies based on correlational types of analyses.²⁶ All analyses were carried out with spss version 22 for Windows (SPSS, Chicago, IL, USA).

Results

Sample characteristics

The sampling flow chart is presented in Figure 1. The initial sample included 68 persons of the 220 invited caregivers (overall response rate 31%, range 22–35%). Only participants who completed at least one of the three questionnaires were included (n=63). Of the 63 participants, one participant did not fill in the GAIN, and four participants did not fill in the PAC. Table 1 shows the sample descriptives and sum scores of the questionnaires.

The missing completely at random test for the sum score of the PES, GAIN, PAC, and FAVS-D connection and experiences score was not significant (P=0.280). Missing data on individual items were imputed for all cases with a minimum of 75% complete data. The percentages of cases with imputed data were: PES 10%, GAIN 10%, PAC 5%, and FAVS-D connection and experiences score 11%.

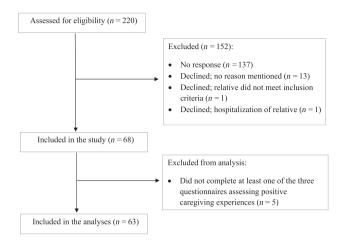


Figure 1 Sampling flow chart.

Descriptives of the items of each questionnaire are presented in Table 2. The majority of our sample were female caregivers (71%) with an average age of 59.2 years (SD 11.8 years), who cared for their parent (59%). The scores clustered toward the high end of the PES, with 18% of the participants receiving the highest possible sum score. For the GAIN and PAC, this was 3% and 4% respectively. No floor effects were observed.

Internal consistency

Cronbach's α -values obtained for the sum scores of the PES, GAIN and PAC were 0.68, 0.90 and 0.94, respectively. Cronbach's α -values for the PAC dimensions self-affirmation and outlook on life were 0.91 for both dimensions. Deleting single items from any of the three questionnaires would not result in higher α -coefficients.

Convergent validity

A strong correlation was observed between the PAC dimensions (r = 0.91). Correlations between the PES, GAIN and PAC sum score, and the FAVS-D connection and experiences score and VAS are presented in Table 3. The PES correlated moderately with the PAC and GAIN. The GAIN correlated strongly with the PAC. The VAS correlated moderately with the PES, GAIN and PAC. The FAVS-D connection and experiences score correlated moderately with the PAC, and weakly with the PES and GAIN.

User-friendliness

Overall, 40% of caregivers preferred the PES, 11% the GAIN, 5% the PAC and 33% did not have any preference. None of the caregivers commented on why they preferred a certain questionnaire.

Of the participants, 18% indicated that they had asked for help of a second person to fill in the questionnaires. The mean number of missing items for the PES was 0.2 (SD 0.5), with 3% missing one item and 6% missing two items. For the GAIN, it was 0.6 (SD 1.7), with 6% missing one item, 2% missing two items and 8% missing three to five items. The mean number of missing items for the PAC was 0.9 (SD 2.5), with 5% missing one item and 5% missing five to eight items. Table 2 shows which items caregivers marked as not relevant and unclear.

The qualitative data showed why caregivers rated items of the PES as not relevant; the care recipient was unable to speak and caring for a relative was thought of as "something you must do whether or not you receive appreciation". Some caregivers found

Table 1 Sample characteristics and descriptives for the questionnaires measuring positive caregiving experiences

	n	%/Mean (SD)	Range
Age of caregiver (years)	63	59.2 (11.8)	25–99
Sex of caregiver	63		
Women	45	71%	
Men	18	29%	
Relationship with person with dementia	63		
Spouse/partner	11	18%	
Son or daughter	37	59%	
Son- or daughter-in-law	6	9%	
Brother or sister	2	3%	
Guardian or mentor	2	3%	
Other	5	8%	
Highest educational level caregiver	62		
No formal education	1	2%	
Primary school	2	3%	
Secondary school	29	46%	
Higher education	30	48%	
Years in nursing home	63	3.1 (2.9)	0.2-17.0
Dementia severity [†]	49	16.6 (4.6)	7–28
Positive Experiences Scale (PES)	63	20.3 (3.1)	10-24
Gain in Alzheimer's Care Instrument (GAIN)	58	25.9 (8.6)	0-40
Positive Aspects of Caregiving measure (PAC)	56	29.4 (9.0)	9–45
VAS	57	6.9 (1.8)	1–10
FAVS-D connection and experiences score	57	3.5 (4.1)	-11-10

†Measured with the Bedford Alzheimer Nursing Severity-Scale by nursing staff, possible range 7–28, and Family Visit Scale for Dementia connection and experiences score (FAVS-D; sum-score items 1–4, 7, 14) possible range –12 to 12.

the item about "appreciation" unclear ("Appreciation from whom? My relative? Staff?"). Several caregivers mentioned they did not like the PAC items suggesting that they should feel better due to their caregiving tasks: "Providing care for my mother is something I do for her. There is no added value for myself in doing that and what others think of it is completely irrelevant to me". Three caregivers mentioned that the GAIN item "increased my knowledge and skills in dementia care and more" was less relevant for them due to their profession as healthcare professional ("I already know most things because I work as a nurse"). A few caregivers mentioned that caring for someone can also be burdensome and difficult; it is not only positive.

Factors related to positive caregiving experiences

The PES, GAIN and PAC were not associated with sex, the relationship with the care recipient, years the care recipient resided in the nursing home and severity of dementia (Table 3). The PES weakly correlated with age (r=0.25), indicating that older caregivers had more positive caregiving experiences. A weak negative association with education level was found for the PES ($r_s=-0.35$), GAIN ($r_s=-0.29$) and PAC ($r_s=-0.28$). Higher educated caregivers had less positive caregiving experiences.

Discussion

The present study compared the internal consistency, convergent validity and user-friendliness of the PES, GAIN and PAC among caregivers of nursing home residents with dementia in the

Netherlands. The questionnaires had acceptable convergent validity. The GAIN and PAC were internally consistent, the PES almost. A ceiling effect for the PES was observed. The PES was preferred by most caregivers. Lower educated caregivers had more positive caregiving experiences. Although all three questionnaires can be used to assess positive caregiving experiences, the GAIN might be the most suitable for caregivers of nursing home residents with dementia.

The convergent validity of the PES, GAIN and PAC was acceptable. This indicates that all three instruments can be used to assess positive caregiving experiences among caregivers of nursing home residents with dementia. The correlation between the GAIN and PAC was comparable to the correlation found among caregivers of community-dwelling persons with dementia (r=0.68). In line with previous research in the community setting, we found a strong correlation between the two PAC dimensions. ²⁷

The GAIN and PAC had acceptable internal consistency, the PES was close to reach the threshold for acceptable consistency. This might be because the PES was not specifically designed for caregivers of people with dementia. Internal consistency of the GAIN and PAC in the present study was comparable to those reported in the community setting (GAIN: 0.88–0.89, PAC: 0.87–0.89). Io.12,27–29 When using the PES in dementia caregivers, the developers suggested to use the six-item version. Excluding these two items did not increase the internal consistency. However, the item "appreciation" was most often seen as not relevant according to the caregivers in our sample. Based on the findings, we advise a conservative approach regarding removing items when using the PES with caregivers of nursing home residents with dementia.

¹ Positive Experiences Scale possible range 8–24; Gain in Alzheimer Care INstrument possible range 0–40; Positive Aspects of Caregiving measure possible range 1–45.

SD, standard deviation; VAS, visual analog scale for self-rated positive caregiving experiences, possible range 0-10.

Table 2 User-friendliness of the Positive Experiences Scale, Gain in Alzheimer's Care Instrument, and Positive Aspects of Caregiving measure

Positive Experiences Scale	n	% missing	Item mean (SD)		% (n) "not relevant".	% (n) "not clear"	ear"	Item distribution (%)	tion (%)	
(PES) ¹⁴ †							Agree	e Do not agree/ do not disagree	se/ ree	Disagree
1. I enjoy the happy moments I have with my relative.	63	0	2.89 (0.36)		3.2 (2)	1.6 (1)	2%	%8		%06
2. Caring for my relative makes me feel good.	63	0	2.79 (0.48)		4.8 (3)	1.6 (1)	3%	14%		83%
3. I get a lot of appreciation for the help I provide.*	09	W	2.52 (0.68)		12.7 (8)	4.8 (3)	10%	. 28%		%79
4. During the period that I have been providing care, my relative and I have grown closer.	62	72	2.23 (0.78)		6.3 (4)	3.2 (2)	21%	35%		44%
5. As a result of providing care, I have learned to be happy about little things.	61	ю	2.54 (0.70)		9.5 (6)	1.6 (1)	12%	23%		%59
6. As a result of providing care, I have learned new things myself.	61	ю	2.72 (0.52)		4.8 (3)	3.2 (2)	3%	21%		%92
7. As a result of providing care, I have met new people.	62	7	2.11 (0.79)		6.3 (4)	1.6 (1)	26%	37%		37%
8. Helping has made my relationship with my family and friends closer.*	62	5	2.58 (0.67)		7.9 (5)	1.6 (1)	10%	23%		%29
Gain in Alzheimer's Care	и	% missing	Item mean (SD)	(u) %	(u) %			Item distribution (%)		
Instrument (GAIN) ¹⁰⁷ Providing care to my relative/loved one has				"not relevant"	"not clear"	Disagree a lot	Disagree a little	Neither agree or disagree	Agree a little	Agree a lot
1 helped to increase my patience and be a more understanding person.	62	2	2.81 (1.16)	3.2 (2)	1.6 (1)	%8	%0	79%	29%	34%
2 made me a stronger and more resilient person.	59	9	2.36 (1.16)	6.3 (4)	(0) 0	%8	12%	32%	31%	17%
3 increased my self-awareness, making me more aware of myself.	59	9	2.44 (1.22)	6.3 (4)	1.6 (1)	%8	12%	31%	25%	24%
 increased my knowledge and skills in dementia care and more. 	62	2	3.13 (1.02)	3.2 (2)	1.6 (1)	2%	2%	11%	40%	42%
5 helped me grow closer to my relative/loved one with dementia.	57	10	2.82 (1.12)	6.3 (4)	3.2 (2)	2%	7%	19%	37%	32%
6 helped to bond my family closer.	59	9	2.36 (1.34)	6.3 (4)	1.6 (1)	15%	%8	24%	31%	22%
										(Continues)

Table 2 Continued

Gain in Alzheimer's Care	и	% missing	Item mean (SD)	(u) %	(u) %			Item distribution (%)		
Instrument (GAIN) ¹⁰⁷ Providing care to my relative/loved one has				"not relevant"	"not clear"	Disagree a lot	Disagree a little	Neither agree or disagree	Agree a little	Agree a lot
7 enabled me to better relate to older persons and persons with dementia.	09	N	3.08 (1.01)	3.2 (2)	3.2 (2)	3%	3%	17%	35%	42%
8 given me deeper insights into the meaning of life and my life's perspective.	59	9	2.54 (1.29)	6.3 (4)	1.6 (1)	12%	%2%	29%	25%	75%
9 helped me grow spiritually.	27	10	1.98 (1.37)	9.5 (6)	0) 0	23%	%6	31%	21%	16%
10 sparked off altruistic goals in me.	59	9	2.47 (1.24)	6.3 (4)	1.6 (1)	10%	7%	34%	24%	25%
Positive Aspects of Caregiving	и	n % missing	g Item mean (SD)	(u) %				Item distribution (%)		
measure (PAC) ^{12.8} Providing help to my relative/loved one has				"not relevant"	"not clear"	Disagree a lot	Disagree a little	Neither agree or disagree	Agree a little	Agree a lot
1 made me feel more useful.	56	5 11	3.27 (1.17)	6.3 (4)	3.2 (2)	11%	11%	34%	30%	14%
2 made me feel good about myself.	. 57	7 10	3.23 (1.21)	6.3 (4)	1.6 (1)	14%	2%	35%	30%	14%
3 made me feel needed.	57	7 10	3.61 (1.31)	9.5 (6)	1.6 (1)	11%	7%	26%	23%	33%
4 made me feel appreciated.	57	7 10	3.42 (1.18)	7.9 (5)	1.6 (1)	%2	14%	30%	28%	21%
5 made me feel important.	56	6 11	2.91 (1.15)	9.5 (6)	1.6 (1)	16%	14%	40%	23%	7%
6 made me feel strong and confident.	57	7 10	3.05 (1.25)	6.3 (4)	1.6 (1)	17%	%6	37%	25%	12%
7 enabled me to appreciate life more.	55	5 13	3.55 (1.12)	6.3 (4)	1.6 (1)	7%	7%	29%	37%	20%
8 enabled me to develop a more positive attitude toward life.	57	7 10	3.12 (1.15)	6.3 (4)	1.6 (1)	12%	12%	37%	78%	11%
9 strengthened my relationships with others.	28	8	3.38 (1.18)	6.3 (4)	1.6 (1)	10%	2%	41%	23%	21%

†Written permission to reproduce the items from the first author.

*Items advised to exclude when using the PES in caregivers of people with dementia.

*Pre-approved permission Sage Publishing; as stated on their website, they allow republishing of no more than a total of 200 words or 10% of the article, whichever is less, from a single journal article within a new publication. ¹⁷ SD, standard deviation.

Table 3 Correlations among the questionnaires measuring positive caregiving experiences, and with family caregiver and care recipient characteristics

Positive caregiving experiences	PES	GAIN	PAC
PES			
GAIN	0.50***		
PAC	0.57***	0.76***	
VAS	0.53***	0.46***	0.51***
FAVS-D connection and experiences score	0.34*	0.31*	0.48***
Caregiver and care recipient characteristics	PES	GAIN	PAC
Age	0.25*	0.07	0.11
Education [†]	-0.35**	-0.29*	-0.28*
Sex	-0.18	-0.07	-0.02
Relationship with care recipient [†]	-0.00	0.02	0.01
Dementia severity [‡]	0.03	-0.18	0.10
Years in nursing home	-0.10	0.03	-0.12

^{*}P < 0.05.

FAVS-D, Family Visit Scale for Dementia, we created a connections and experiences score by summing items 1–4, 7 and 14; GAIN, Gain in Alzheimer Care INstrument; PAC, Positive Aspects of Caregiving measure; PES, Positive Experiences Scale; VAS, visual analog scale for perceived positive caregiving experiences.

The PES performed best on user-friendliness, with the least missing data and being preferred by most caregivers, followed by the GAIN. Previously suggested disadvantages of the GAIN are that some items contain concepts that might be difficult to understand for caregivers, and that certain items ask about more than one gain simultaneously, which might cause confusion. One of the caregivers reported confusion about GAIN items that ask about more than one gain simultaneously, and the concepts in the items seemed clear to the caregivers. The number of unclear items in the GAIN was comparable to the PES and PAC. Nevertheless, the PAC was least often preferred by caregivers and had that most items that caregivers deemed not relevant.

In the present study, positive caregiving experiences were not associated with caregiver sex, relationship with care recipient, years the care recipient resided in a nursing home or the severity of dementia. However, higher educated caregivers experienced less positive caregiving experiences. This negative association has also been found in previous research. ^{28,29,31} Kramer suggested that higher educated caregivers might perceive a more prominent status disparity between their role as a professional and their role as caregiver.31 Highly educated caregivers might be used to being engaged in more intellectually stimulating activities, which can make it difficult to perceive the caregiving tasks as rewarding. These results suggest that interventions should specifically target highly educated caregivers to help them identify positive caregiving experiences. Only for the PES, older caregivers experienced more positive caregiving experiences. More research is required, as these were only explorative analyses.

The present study had several limitations. The convenience sample of nursing homes and low response rate might limit the generalizability of the results. The present sample consisted of self-selecting caregivers, who were able to complete the questionnaires independently or were able to ask someone to assist them. It could be that more severely distressed caregivers did not participate in the present study. The order of the

questionnaires was not randomized. Also, we examined a few psychometric qualities of three questionnaires. Future studies should compare more questionnaires measuring positive caregiving experiences and compare them on other psychometric qualities for a more detailed picture.

Despite its limitations, the present study is the first examining both psychometric qualities and user-friendliness of three questionnaires assessing positive caregiving experiences, and compared them for the use among caregivers of nursing home residents with dementia. Our study solicited for evaluation and comparison of the questionnaires directly in the target population of family caregivers. All three questionnaires can be used to assess positive caregiving experiences among caregivers of nursing home residents with dementia. However, the GAIN might be more suitable for this population, based on its performance on internal consistency and convergent validity, and its user-friendliness despite not being caregivers' preferred questionnaire. A review about positive psychology measures scored the GAIN the highest on the quality assessment criteria. 11 The GAIN is an easily administered questionnaire that can be used to evaluate positive caregiving experiences among caregivers of people with dementia in long-term care. Positive caregiving experiences might buffer to ameliorate the stress of caregiving. Insights into positive caregiving experiences and associated factors can help to optimize interventions for family caregivers and to learn about adaptation to chronically stressful circumstances to improve their well-being.

Acknowledgements

We would like to thank Giselka Gutschow and Celine Neefkes-Zonneveld for their support in collecting the data, and Philip Yap for help with the translation of the GAIN. This study was funded by the Netherlands Organisation for Health Research and

^{**}*P* < 0.005.

^{***}*P* < 0.001.

[†]Spearman's rho.

^{*}Measured with Bedford Alzheimer Nursing Severity-Scale by nursing staff.

Development (grant number 733050302), Fonds NutsOhra (grant number 1405-181), and University Network of the Care sector South Holland.

Disclosure statement

The authors declare no conflict of interest.

References

- 1 Wimo A, Reed CC, Dodel R et al. The GERAS study: a prospective observational study of costs and resource use in community dwellers with Alzheimer's disease in three European countries–study design and baseline findings. *J Alzheimers Dis* 2013; **36**: 385–399.
- 2 Ory MG, Hoffman RR III, Yee JL, Tennstedt S, Schulz R. Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *Gerontologist* 1999; 39: 177–186. https://doi.org/ 10.1093/geront/39.2.177%J.
- 3 Tornatore JB, Grant LA. Burden among family caregivers of persons with Alzheimer's disease in nursing homes. *Gerontologist* 2002; 42: 497–506. https://doi.org/10.1093/geront/42.4.497.
- 4 Joling KJ, Windle G, Dröes RM et al. Factors of resilience in informal caregivers of people with dementia from integrative international data analysis. Dement Geriatr Cogn Disord 2016; 42: 198–214. https://doi.org/ 10.1159/000449131.
- 5 Quinn C, Clare L, Woods RT. Balancing needs: the role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia* 2015; 14: 220–237.
- 6 Yu DSF, Cheng S-T, Wang J. Unravelling positive aspects of caregiving in dementia: an integrative review of research literature. *Int J Nurs Stud* 2018; 79: 1–26. https://doi.org/10.1016/j.ijnurstu.2017.10.008.
- 7 Quinn C, Toms G. Influence of positive aspects of dementia caregiving on caregivers' well-being: a systematic review. *Gerontologist* 2019; 59: e584–e596.
- 8 Rapp SR, Chao D. Appraisals of strain and of gain: effects on psychological wellbeing of caregivers of dementia patients. *Aging Ment Health* 2000: 4: 142–147.
- 9 Pinquart M, Sörensen S. Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: a meta-analytic comparison. Aging Ment Health 2004; 8: 438–449.
- 10 Yap P, Luo N, Ng WY, Chionh HL, Lim J, Goh J. Gain in Alzheimer care instrument: a new scale to measure caregiving gains in dementia. Am J Geriatr Psychiatry 2010; 18: 68–76.
- 11 Stansfeld J, Stoner CR, Wenborn J, Vernooij-Dassen M, Moniz-Cook E, Orrell M. Positive psychology outcome measures for family caregivers of people living with dementia: a systematic review. *Int Psychogeriatr* 2017; 29: 1281–1296. https://doi.org/10.1017/S1041610217000655.
- 12 Tarlow BJ, Wisniewski SR, Belle SH, Rubert M, Ory MG, Gallagher-Thompson D. Positive aspects of caregiving: contributions of the REACH project to the development of new measures for Alzheimer's caregiving. Res Aging 2004; 26: 429–453.
- 13 Liew TM, Luo N, Ng WY, Chionh HL, Goh J, Yap P. Predicting gains in dementia caregiving. *Dement Geriatr Cogn Disord* 2010; 29: 115–122.
- 14 De Boer AH, Oudijk D. Broese van Groenou MI, Timmermans JM. Positieve ervaringen door mantelzorg: constructie van een schaal [positive experience through informal care: construction of a scale]. *Tijdschr Gerontol Geriatr* 2012; 43: 243–254.
- 15 Bramble M, Moyle W, McAllister M. Seeking connection: family care experiences following long-term dementia care placement. *J Clin Nurs* 2009; 18: 3118–3125.

- 16 Smaling HJA, Joling KJ, van de Ven PM et al. Effects of the Namaste care family programme on quality of life of nursing home residents with advanced dementia and on family caregiving experiences: study protocol of a cluster-randomised controlled trial. BMJ Open 2018; 8: e025411.
- 17 SAGE Publications. Pre-Approved Permission Requests. London: SAGE Publishing, 2021 https://uk.sagepub.com/en-gb/eur/pre-approved-permission-requests-journals. Accessed April 13, 2021.
- 18 Sanford AM, Orrell M, Tolson D *et al*. An international definition for "nursing home". *J Am Med Dir Assoc* 2015; **16**: 181–184.
- 19 World Health Organization. Process of translation and adaptation of instruments. https://www.who.int/substance_abuse/research_tools/ translation/en/. Accessed November 16, 2020
- 20 Fuchs C, Diamantopoulos A. Using single-item measures for construct measurement in management research: conceptual issues and application guidelines. *Die Betriebswirtschaft* 2009; 69: 195.
- 21 Volicer L, DeRuvo L, Hyer K, Piechniczek-Buczek J, Riordan ME. Development of a scale to measure quality of visits with relatives with dementia. *J Am Med Dir Assoc* 2008; **9**: 327–331.
- 22 Volicer L, Hurley AC, Lathi DC, Kowall NW. Measurement of severity in advanced Alzheimer's disease. J Gerontol Med Sci 1994; 49: M223– M226. https://doi.org/10.1093/geronj/49.5.M223.
- 23 van der Steen JT, Volicer L, Gerritsen DL, Kruse RL, Ribbe MW, Mehr DR. Defining severe dementia with the minimum data set. Int J Geriatr Psychiatry 2006; 21: 1099–1106.
- 24 Bland JM, Altman DG. Statistics notes: Cronbach's alpha. *BMJ* 1997; 314: 572.
- 25 Roth PL, Switzer FS III, Switzer DM. Missing data in multiple item scales: a Monte Carlo analysis of missing data techniques. *Organ Res Methods* 1999; 2: 211–232.
- 26 De Vet HC, Terwee CB, Mokkink LB, Knol DL. Measurement in Medicine: A Practical Guide. Cambridge: Cambridge University Press, 2011.
- 27 VWQ L, Lau BH-P, Cheung KS-L. Positive aspects of caregiving (PAC): scale validation among Chinese dementia caregivers (CG). Arch Gerontol Geriatr 2015; 60: 299–306. https://doi.org/10.1016/j.archger. 2014.10.019.
- 28 Gonçalves-Pereira M, Carmo I, da Silva JA, Papoila AL, Mateos R, Zarit SH. Caregiving experiences and knowledge about dementia in Portuguese clinical outpatient settings. *Int Psychogeriatr* 2010; 22: 270–280.
- 29 García-Castro FJ, Alba A, Blanca MJ. The role of character strengths in predicting gains in informal caregivers of dementia. *Aging Ment Health* 2019; 25: 1–6.
- 30 Fabà J, Villar F, Giuliani MF. Development of a measure to evaluate gains among spanish dementia caregivers: the gains associated with caregiving (GAC) scale. *Arch Gerontol Geriatr* 2017; **68**: 76–83. https://doi.org/10.1016/j.archger.2016.09.004.
- 31 Kramer BJ. Differential predictors of strain and gain among husbands caring for wives with dementia. *Gerontologist* 1997; **37**: 239–249.

How to cite this article: Smaling HJA, Joling KJ, Achterberg WP, Francke AL, van der Steen JT. Measuring positive caregiving experiences in family caregivers of nursing home residents: A comparison of the Positive Experiences Scale, Gain in Alzheimer Care INstrument, and Positive Aspects of Caregiving questionnaire. Geriatr. Gerontol. Int. 2021;21:636–643. https://doi.org/10.1111/ggi.14210