RESEARCH NOTE



Participation factors in a self-quantification program for family caregivers of communitydwelling older adults with long-term care in Japan

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Abstract

Objective This study aimed to examine the characteristics of participation in the self-quantification program for family caregivers (CGs) who provide long-term care to community-dwelling older adults. The family CGs, allocated based on the percentage of the nation's older population who needed care and met the inclusion criteria, who provided caregiving at least once a week for those aged 65 + and who were certified as needing care under the Japanese long-term care insurance program, were collected through online monitors. We compared the characteristics of the program participants and nonparticipants using logistic regression.

Results A total of 2653 family CGs, including 195 study participants who engaged in self-quantification over 60 days and 2,458 nonparticipants who did not engage in self-quantification, were included in the analysis, with complete data available for all variables of interest. The survey included program participants who were predominantly male (55.9%), with an average age of 54.8 years (SD = 10.2). Participants tended to be fully employed (OR = 1.8; p < 0.01), but they were likely to experience greater burdens (OR = 1.8; p < 0.01) and daily caregiving demands (OR = 1.01; p < 0.01). This research highlights the potential efficacy of self-quantification programs for extensively burdened family CGs, illustrating that the requisites for support vary in accordance with the distinct characteristics of these CGs.

Keywords Family, Self-quantification, Support program, Volunteer bias, Caregivers, Burden

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Introduction

In Japan, the older adult population, referred to as "the post-war baby boomer generation," is now reaching the age of 75 and older. The rapid increase in the number of this "old-old" generation who start to require long-term care is becoming a significant social concern. This demographic shift is mirrored by the significant increase in the number of family caregivers (CGs) providing support to community-dwelling older adults who require care [1]. Under these circumstances, it is extremely important that we develop effective support programs to reduce the burden of caregiving. Previous research revealed that family CGs report high levels of burden as well as health impairments and consequently state a high number of perceived needs for more support and assistance [2, 3]. However, due to their time-consuming responsibilities and greater burden, they often deny themselves to engage in peer support [3]. Furthermore, a variety of support programs have contributed to the psychological wellbeing of family CGs; however, the results of these studies are inconsistent [2, 4, 5]. One of the challenges in providing support programs is insufficient tailoring of programs to the interests of the target population [2, 4].

Daily fluctuations in care have received increasing attention and are a critical factor related to caregiving stress [6–9]. People have various daily emotional states that contribute to their mental health [10]. Furthermore, caregiving for older adults involves daily challenges that are both unpredictable and stressful. These challenges primarily stem from the fluctuating physical and cognitive conditions of the care recipients (CRs) [8], and CGs must continuously adjust to day-to-day stressors, which can be mentally and emotionally draining.

Self-quantification, as delineated in the review by M Almalki, K Gray and F Martin-Sanchez [11], involves individuals measuring their own physical, mental, and emotional aspects of daily life. This method could be a valuable strategy for managing daily stress and enhancing overall physical and mental well-being. It significantly influences behavior modification. By gaining insights into their own conditions, individuals can detect trends in their health and adjust their responses, devise strategies, or seek external assistance [11, 12]. This conceptual approach can be extended to family caregiving. Echoing the documented advantages of diary-keeping [13-15], family CGs can, through introspection, discern patterns in the needs of those they care for, thus enhancing their own and their CRs' quality of life and well-being while decreasing their own caregiving strain, all within the ambit of daily caregiving self-quantification.

Based on the above rationale, we developed a selfquantification support program for family CGs called CARE-VIP, which focuses on measuring daily care. Selfquantification may serve as a great support for family CGs to improve their physical and psychological wellbeing [12], but we have overlooked the preferences for self-quantification by family CGs. Self-quantification may place an extra time burden on reporting everyday tasks of caregiving to use their time for those already in time-consuming situations, which may protect against engaging in the program due to the extra workload [9]. Although more severely burdened individuals seek more support, more severely burdened individuals are less likely to join support programs, as shown by volunteer bias [16]. Moreover, studies have shown that male CGs are less frequently included in surveys [17] and are less inclined to participate in support programs [18]. Selection biases, such as more active, health-conscious individuals who are able to participate in health improvement programs, are also common in general [19]. Examining engagement factors is important for providing programs for intervention and evaluating the feasibility of installing such programs in the real world. This study aimed to examine the participation characteristics of family caregivers (CGs) providing long-term care to community-dwelling older adults based on a self-quantification program.

Main text

Study overview and study design

This study is part of a prospective observational project titled the Caregiving Visualization Project (CARE-VIP), investigating the impact of self-quantification practices among these CGs concerning their caregiving tasks and daily lives. The project was prospectively designed to investigate the daily, medium-term, and long-term impacts of caregiving and everyday life activities on both negative and positive perceptions among family CGs of community-dwelling older adults starting in April 2023.

Program development

We developed the CARE-VIP, an online tool that enables family CGs to record daily caregiving activities via a website accessible from computers or smartphones. The program directs participants to complete a survey on caregiving and their everyday life twice a day and to track their sleep and walking steps using actigraphy (MTN-210) [20] during the day and at night but not at bath time. Reminder emails were sent each morning and evening to prompt completion of the questionnaires. The morning questions covered sleep details (in-bed and wake-up times, quality, disruptions) and self-rated mood. The evening questions focused on self-rated health and emotional status, including information about caregiving activities, receiving social support, and CRs' service usage. Participants were instructed to use CARE-VIP and actigraphy for 60 consecutive days. Study participants received approximately US\$120 (¥16,000) upon completing the survey.

Sampling procedure

The eligibility criteria for family members included (1) being 20 years old and older, (2) self-reporting the provision of care to at least one community-dwelling older adult who was 65 years and older and certified as needing care under the Japanese long-term care insurance program [21], and (3) the family member themselves must not be institutionalized. Using these criteria, the study participants were selected using a three-step process from individuals who are pooled by a survey company to create a diverse and representative group of respondents for their surveys.

Step 1: Initially, a screening survey was distributed to a pool of 826,938 individuals registered with the survey company MyVoice Communications, Inc [22]. This initial screening identified 5,490 eligible family caregivers who met the above criteria from 155,604 respondents.

Step 2: Eligible CGs were given a detailed caregiving survey, considered the base survey, to gather information on their caregiving activities, burden, depression levels, and care requirements. A total of 3256 family CGs completed this survey, forming a potential participant pool.

Step 3: To recruit CARE-VIP participants engaged in frequent caregiving, we selected CGs who (a) actively provided care at least once a week and (b) possessed

a smartphone capable of installing the actigraphy app. Among these, 2,743 selected family CGs were then invited to participate in the program. Initially, 372 (13.6%) family CGs agreed to participate online. Subsequently, 210 (7.7%) family CGs consented to participate both online and via phone, following a detailed phone call that confirmed their participation and explained the study requirements. Participants were asked to wear an actigraphy device and record their daily caregiving activities, social interactions, subjective sleep conditions, and emotional outcomes for 60 consecutive days.

During the set-up process of actigraphy app and CARE-VIP diary, nine participants (4.3%) withdrew before the CARE-VIP program started, and 6 of the study participants had missing data. Among the nonparticipants, 84 had missing variables. The final sample size for the analysis was 2,653, comprising 195 study participants from CARE-VIP and 2,458 nonparticipants who did not engage in self-quantification while responding to the base survey. The details are shown in Fig. 1.

Instruments

The analyzed variables were defined based on previous papers and were selected based on the stress process model developed by Pearlin and his colleagues [23]. This



Fig. 1 Chart participant selection and data collection process for the CARE-VIP program

model provides a framework for understanding relationships among stressors, mediators, and outcomes. The selected variables correspond to the model's key components, including primary stressors (e.g., care demands), secondary stressors (e.g., financial strain), mediators (e.g., social support), and outcomes (e.g., caregiving burden), which defined participation. These variables were chosen for their relevance to the model's pathways. The following basic demographics of the CGs were included in the model: sex, age, marital status, employment status, and financial status. Self-rated health was assessed as a general health indicator (poor, fair, neither, good, or excellent). Basic demographics of the CRs, age, relationships with CGs, and coresidence with CGs. A total of 12 basic and instrumental activities of daily living (ADLs and IADLs) were assessed. These activities included bathing, dressing, toileting, mobility, continence, and feeding for ADLs as well as meal preparation, shopping, cleaning, medication management, financial management, and going out for IADLs [24, 25]. Each activity was scored as 0 (dependent), 1 (partially dependent), or 2 (independent), and the scores were summed across all dimensions, resulting in a total range of 0 to 24, with higher scores indicating greater levels of independence. The presence of dementia-related symptoms was also assessed. Caregiving-related variables included care frequency per week and duration of caregiving. Those with instrumental, emotional, or informational support from family or friends, respectively, were also asked (yes/no/ DK), in order to examine the impact between social support and the current program. CGs' psychological outcomes were assessed with the Japanese version of the Zarit Caregiver Burden Inventory (ZBI) [26], and depression was measured with the Japanese version of the Center for Epidemiologic Studies Depression Scale (CES-D) [27] to measure symptoms of depression in family caregivers based on Radloff's CES-D scale [28]. Each item on the Zarit Burden Interview (ZBI) is scored from 0 (never) to 4 (nearly always), with a total score ranging from 0 to 88, indicating the severity of caregiver burden. In this sample, internal consistency was high, with a Cronbach's alpha of 0.955. Similarly, each item on the Center for Epidemiologic Studies Depression Scale (CES-D) is scored from 0 (rarely or none of the time) to 3 (most or all of the time), with a total score ranging from 0 to 60, indicating the severity of depressive symptoms. Internal consistency for this sample was also high, with a Cronbach's alpha of 0.898.

Data analysis

In this study, we compared the baseline characteristics of the study participants and nonparticipants to examine their participation in the self-quantification program by χ^2 tests (for categorical variables) and t tests

(for continuous variables) for bivariate analysis. We also assessed the effect sizes for variables that demonstrated significance in the univariate analysis, using Cramer's V for categorical variables and Cohen's d for continuous variables [29, 30].

Afterward, to prevent data contamination due to the strong correlation between depression and perceived caregiving burden, separate logistic regression models were constructed to analyze the impact of caregiving burden and depression on participation in self-quantification programs. The independent variables included the CG's gender, marital status, and employment status; the CG-CR relationship; and the CR's living arrangement, dementia symptoms, and social support. All of these variables were treated as categorical variables. The following continuous variables were also considered: the CG's age, self-rated health (where higher scores indicate poorer health), and financial status (with higher scores indicating poorer financial condition); the CR's age, ADL (with higher scores indicating greater independence), and caregiving frequency; and caregiving duration.

For the models, VIF (1.04–3.60) indicated nonsignificant collinearity among independent variables. In this study, a significance level of 95% was employed to determine the statistical significance of the results. These analyses were performed using IBM SPSS ver. 29.0.

Ethical considerations

This study was ethically approved by Tokyo Metropolitan Institute of Gerontology Institutional Review Board, No. R21-076. This study complied with the Declaration of Helsinki and its amendments or comparable ethical standards for conducting surveys that included an initial questionnaire, a self-quantification program, a followup questionnaire, and interviews. Informed consent was obtained from all participants via online methods.

Results

The overall survey sample included 51.3% female participants, with an average age of 55.8 years. In contrast, the program participants were predominantly male (55.9%) with an average age of 54.8 years (SD=10.2). The details are shown in Table 1.

Bivariate analysis revealed that the study participants included more full-time employees (p<0.001), individuals with poorer self-rated health (p=0.032), individuals with a lower financial situation (p=0.017), and individuals who provided more frequent care (p=0.044). This group also exhibited greater caregiving burdens (p<0.001) and greater depression scores (p=0.004). These findings are shown in Table 1.

Logistic regression accounting for demographics, caregiving-related variables, and caregiving burden indicated that male sex (OR=1.44, p=0.041), full-time

Characteristics	Total (%)	Particinants (%)	Non-narticinants (%)	Difference among groups	Effect size
	(n=2653)	(<i>n</i> =195)	(n=2458)	(P values)	Lifect Size
CG gender				0.076 ^a	
Female	51.3	43.6	51.9		
Male	48.4	55.9	47.8		
DK	0.3	0.5	0.3		
CG age, [Mean (SD)]	55.8 (11.0)	54.8 (10.2)	55.9 (11.0)	0.193 ^b	
Marital status				0.825 ^a	
Unmarried	31.2	30.3	31.3		
Married	59.7	59.5	59.7		
Divorced/Deceased	9.1	10.3	9		
Employment				< 0.001 ^a	0.083
Unemployed	33.2	25.6	33.8		
Employed Fulltime	50.3	64.6	49.1		
Employed Parttime	14.5	8.7	15		
Employed Others	2	1	2		
Self-rated health				0.032 ^a	0.063
Excellent	5.8	7.2	5.7		
Good	47.9	46.7	48		
Neither	18.2	14.4	18.5		
Fair	21.4	20	21.5		
Poor	6.7	11.8	6.3		
Financial status				0.017 ^a	0.067
Very wealthy	8.1	8.7	8.1		
Relatively wealthy	27.7	27.7	27.7		
Neither	28.7	19	29.5		
Relatively poor	19.2	24.6	18.8		
Very poor	16.3	20	16		
CR relationships				0.845 ^a	
Spouse	6.4	5.6	6.5		
Mom	51.6	53.3	51.5		
Dad	20.4	20.5	20.4		
MI	10	8.7	10.1		
Grandparents	58	46	59		
Others	5.7	7.2	5.6		
CR age [Mean (SD)]	848(79)	84 1 (7 8)	849(79)	0.187 ^b	
Coresidence	0 110 (715)	0 (7.0)	0.13 (7.13)	1.000 ^a	
Live-in	66.8	66.7	66.8	1.000	
Live-out	33.2	33.3	33.2		
	99.2 99.60)	99(59)	99(60)	0.950 ^b	
Noc, (Mean (SD))	9.9 (0.0)	5.5 (5.5)	5.5 (0.0)	0.930 0.245ª	
Voc	64.2	68.2	63.0	0.245	
No	25.8	31.8	36.1		
Caro froquency	55.0	51.0	50.1	0.044a	0.055
Evender	E0 2	67.6	EQ	0.044	0.055
Everyddy	0	11.0	0 0 7		
2 4 days/week	9	11.0	0.7		
2-4 days/week	21.9	20	22.1		
I day/week	10.8	5.6	11.2	0.0003	
Caregiving period (years)	12.2	10.2	12.2	0.089°	
< 1	12.2	10.3	12.3		
1-3	30.6	23.1	31.2		
5-5	25.3	29.7	24.9		
5-10	21.8	26.2	21.5		
>10	10.2	10.8	10.1		

Table 1 Baseline characteristics of survey respondents and univariate analysis

Table 1 (continued)

Characteristics	Total, (%) (n = 2653)	Participants, (%) (n=195)	Non-participants, (%) (n=2458)	Difference among groups (P values)	Effect size
Instrumental support					
Family				0.513 ^a	
None	34	37.4	33.7		
Yes	65.7	62.1	65.9		
DK	0.3	0.5	0.3		
Friend				0.773 ^a	
None	88.7	87.2	88.8		
Yes	10.1	11.3	10		
DK	1.2	1.5	1.2		
Emotional support					
Family				0.710 ^a	
None	24.9	26.2	24.8		
Yes	74.8	73.3	74.9		
DK	0.3	0.5	0.2		
Friend				0.651 ^a	
None	60	59.5	60		
Yes	38.8	40	38.7		
DK	1.2	0.5	1.2		
Informational support					
Family				0.600 ^a	
None	43.7	47.2	43.4		
Yes	55.7	52.3	56		
DK	0.5	0.5	0.5		
Friend				0.809 ^a	
None	68.3	66.7	68.4		
Yes	30.5	32.3	30.3		
DK	1.3	1	1.3		
Caregiver Burden: ZBI (0–88), [Mean (SD)]	37.0 (21.1)	43.1 (22.4)	36.5 (20.9)	< 0.001 ^b	0.307
Depression: CES-D (0–60), [Mean (SD)]	18.1 (10.7)	20.2 (11.3)	17.9 (10.6)	0.004 ^b	0.214

Abbreviations: DK: don't know; MIL: mother-in-law; ZBI: Zarit burden index; CES-D: Center for epidemiologic studies depression scale; SD: standard deviation; CG: caregiver; CR: care recipient; ADL: activity of daily living

^aPearson's Chi-Square test was applied to categorical variables, along with Cramér's V employed to measure the effect size

^bA t-test was applied to continuous variables, with Cohen's D employed to measure the effect size

employment (OR=1.80; p=0.003), higher caregiving frequency (OR=1.28; p=0.008), longer caregiving duration (OR=1.17; p=0.021), and greater caregiving burden (OR=1.01; p=0.002) predicted greater CARE-VIP participation (see Table 2). After controlling for the same variables, depression did not emerge as a significant predictor, showing only a marginal impact (OR=1.02; p=0.055) (Figure not shown).

Discussion

The aim of supporting family CGs in alleviating their emotional strain is challenging in practice due to the limited ability of CGs to seek help, often stemming from time constraints and substantial burdens. This reality results in sampling bias in intervention programs and complicates the delivery of support to those facing more severe burdens. This study revealed the potential of self-quantification to support severely burdened and time-consuming family CGs

First, the study revealed that the family CGs who expressed interest and participated in the program were predominantly male even after controlling for other factors. This is notable given that male CGs are typically less surveyed [17] and are inclined to participate in support programs [18]. The individualized approach of the selfquantification online program rather than peer support or any time-fixed support program appeared particularly appealing to male CGs. Possible reasons for this attraction include greater familiarity with technology among males [31, 32], a preference for individual support over group-based support because of a reluctance to acknowledge their distress [18], and a need for time-efficient support options due to the likelihood of juggling multiple responsibilities of work and caregiving [33]. This time efficiency is supported by our findings, indicating

Table 2 Logistic regression model to relate to program participation (n = 2653)

Characteristics	OR (95% CI)	Pvalues
CG gender		
Female	1.00	
Male	1.44 (1.02–2.04)	0.041
DK	2.64 (0.30–23.62)	0.385
CG age	1.00 (0.97–1.02)	0.694
CG marital status		
Unmarried	1.00	
Married	1.18 (0.79–1.75)	0.428
Divorced/Deceased	1.30 (0.74–2.28)	0.368
CG employment status		
Unemployed	1.00	
Full-time	1.80 (1.22–2.66)	0.003
Part-time	0.79 (0.44–1.42)	0.433
Others	0.70 (0.16-3.10)	0.638
Self-rated health	1.00 (0.86–1.17)	0.979
Financial status	1.02 (0.88–1.17)	0.802
CG-CR relationship		
Spouse	1.00	
Mother	1.04 (0.41–2.66)	0.938
Father	0.92 (0.34–2.55)	0.878
Mother-in-law	0.95 (0.33–2.73)	0.918
Grandparents	0.80 (0.17–3.79)	0.783
Others	1.42 (0.49–4.12)	0.518
CRage	1.00 (0.97–1.03)	0.806
CR living arrangement		
live-in	1.00	
live-out	1.40 (0.94–2.10)	0.097
ADI	1 02 (0 99–1 04)	0 274
Dementia symptoms		
No		
Yes	0.83 (0.59–1.16)	0 274
Caregiving frequency	1 28 (1 07–1 54)	0.008
Caregiving period	1 17 (1 02–1 34)	0.021
Instrumental from family (none)		0.021
Yes	0.84 (0.55–1.28)	0.419
DK	1 74 (0 12-24 68)	0.683
Instrumental from friend (none)		0.005
Yes	0 90 (0 53–1 54)	0 705
DK	1 31 (0 28–6 09)	0.730
Emotional from family (none)	1.51 (0.20 0.09)	0.750
Yes	1 30 (0 82-2 07)	0.263
DK	4 56 (0.23–91 84)	0.322
Emotional from friend (none)	1.50 (0.25 51.01)	0.522
	1 02 (0 68-1 54)	0.930
DK	0.16(0.01 + 3.21)	0.230
Information from family (nono)	0.10 (0.01-3.21)	0.229
	0.72 (0.48, 1.10)	0.126
	$0.75(0.70^{-1.10})$	0.100
Lin	0.52 (0.02-14.54)	0.702
	1 20 (0 78 1 84)	0 402
	1.20 (0.70 - 1.04)	0.403
Caragiving burden	1.00 (0.19 - 14.11) 1.01 (1.00 1.02)	U.04ŏ
	1.01 (1.00-1.02)	0.002

Abbreviations: DK: don't know; MIL: mother-in-law; ZBI: Zarit burden index; CES-D: Center for epidemiologic studies depression scale; CG: caregiver; CR: care recipient; ADL: activity of daily living

that CGs with full-time employment were significantly more interested in the program than those who were not employed. The flexibility to document their caregiving activities at their convenience, without aligning with anyone else's schedule, likely resonated particularly with working men, enhancing the program's appeal

Second, CGs who provided care more frequently and over longer periods showed a stronger preference for this program. In the realm of daily caregiving, frequent CGs often encounter more variability in care demands. A practical strategy to manage these fluctuations involves identifying any patterns in caregiving tasks, which underscores the utility of logging daily activities for CGs. Initially, family caregiving requires understanding available community services, collating various caregiving-related information, and managing daily care needs. Beyond this phase, as CGs settle into their roles, their support needs often evolve. The results indicated that our self-quantification program was particularly appealing to those in the chronic stages of caregiving, offering tools that adapt to the shifting dynamics of long-term care

Third, individuals experiencing severe caregiving burdens were more likely to participate in self-quantification programs. As McKenzie and Joy [16] observed, those heavily burdened are often less inclined to participate in support programs, despite needing support. Heavily burdened CGs frequently encounter unpredictable care situations, making it challenging to commit to fixed-time support programs. The flexible nature of our online, selfpaced program could be particularly appealing to these individuals. Conversely, we only observed a marginal correlation between the severity of depression and program participation. Depression is often a chronic response to continuous caregiving burdens [23]. Those suffering from chronic depression may require different types of interventions, warranting further investigation

Finally, we address the generalizability of this study. Our sample reflects key demographic characteristics of family caregivers in Japan, allowing for reasonable generalization to the broader population. Although our sample had a higher proportion of male caregivers (48.4% vs. 31.1%) and fewer live-in caregivers (66.8% vs. 79.5%) compared to national statistics [34], these differences are not substantial. The sample was diverse in terms of regional representation, age, gender, relationship, employment status, and caregiving experience, supporting the external validity of the findings. However, caution is advised when extending these results to other cultural contexts where caregiving norms and support systems differ. Future studies should replicate these findings across varied settings to confirm broader applicability

Limitations

This study has several limitations that warrant attention. First, this study's methodology, which involved recruiting participants through online platforms, inherently favored individuals with higher levels of digital literacy. To mitigate potential selection bias introduced using an online platform for recruitment, supplemental recruitment strategies could be implemented, targeting women and caregivers who provide care infrequently, often from a distance. Additionally, expanding the number of study participants could further help to reduce bias, ensuring that our sample more accurately reflects the diverse population of caregivers. Furthermore, the incentive structure of our study, which included monetary compensation for participation, introduces another layer of complexity. Although the logistic regression analysis did not reveal a direct correlation between financial status and participation, monetary incentives likely influenced CG engagement with the program. Future research should address these challenges by incorporating a diverse participant pool

Abbreviations

- CG Caregiver
- CR Care recipient
- MIL Mother-in-law
- DK Don't know
- n.s Not significant
- MIL Mother-in-law
- ZBI Zarit burden index
- CES-D Center for epidemiologic studies depression scale
- SD Standard deviation
- ADL Activity of daily living

Author contributions

TW designed, conducted surveys, analyzed data and created the manuscript. SF, TN, YM, and SuO, conducted surveys, interpreted the data analyses, and critically revised and finalized the manuscript for submission. IK, SA, and ShO oversaw this project, supervised the process, and provided each expert opinions. All authors approved the final manuscript for submission.

Funding

This research is funded by the JSPS Grants-in-Aid for Scientific Research (B), grant number 21H03282, and by a grant from the Smart Watch Innovation for Next Geriatrics & Gerontology (SWING-JAPAN) program sponsored by the Tokyo Metropolitan Government.

Data availability

The data used in this study are not available in a public repository because a confidentiality agreement with participants prevents us from sharing the data.

Declarations

Ethics approval and consent to participate

This study was ethically approved by Tokyo Metropolitan Institute of Gerontology Institutional Review Board (No. R21-076) and complied with the Declaration of Helsinki and its amendments or comparable ethical standards for conducting surveys that included an initial questionnaire, a selfquantification program, a follow-up questionnaire, and interviews. Informed consent was obtained from all participants via online methods.

Consent for publication

Not applicable.

Competing interests

SuO declares personal salary as a chief executive officer from BMS Yokohama Inc, but have no conflict of interest regarding the content of this paper. The other authors, TW, SF, YM, TN, ShO, SA, IK declare no conflicts of interest.

Received: 5 June 2024 / Accepted: 2 December 2024 Published online: 26 December 2024

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