Translation and validation of the Thai Version of the Oral Health-related Caregiver Burden Index (OHBI) Among Caregivers of Patients Living with Neurocognitive Disorders

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Abstract

Objectives: To translate and validate a Thai version of the Oral Health-related Caregiver Burden Index (OHBI) for caregivers in Thailand.

Methods: The Japanese OHBI was translated and culturally adapted into Thai through a structured process involving forward and backward translation, expert committee review, and pre-final version testing. These steps were conducted to ensure content and face validity. The Thai OHBI was then administered to caregivers of outpatients at a general hospital in Thailand, assisting patients with major neurocognitive disorders (MNDs) and Parkinson's disease (PD). A minimum of forty-six participants was required, accounting for dropout rates.

Results: The questionnaire was initially administered to sixty caregivers, with forty-seven caregivers completing the follow-up assessment at week two. Internal consistency was acceptable, (Cronbach's alpha: 0.676 to 0.864). Test-retest reliability, assessed using the Intraclass Correlation Coefficient (ICC), ranged from 0.296 to 0.647. The Mann-Whitney U test demonstrated significant discriminant validity. Over 80% of participants reported difficulties in performing oral hygiene care for PD and MNDs patients, and approximately half of the caregivers perceived a burden in providing oral care.

Conclusions: The Thai OHBI demonstrated acceptable reliability and validity. However, further testing in larger caregiver populations is required to confirm its robustness and applicability.

Keywords: aged, caregiver burden, neurodegenerative diseases, oral care, oral hygiene

Introduction

The 2024 National Survey[1] reported that 6.59% of older adults in Thailand require assistance with daily activities. More specifically, 2.05% of older adults needed a caregiver to assist with grooming and maintain their hygiene.[1] Similarly, some of these older adults also depended on caregivers for daily oral hygiene care.[2]

Providing oral care to dependent patients presents various challenges, such as resistant behavior from care recipients, caregiver's lack of experience or knowledge, and discomfort in managing oral hygiene tasks.[3,4] Chalmers J et al.,[5] observed caregivers spent less time on oral care when facing such difficulties. Similarly, Reis et al.,[6] identified daily oral care as a contributing factor to caregiver burden.

In Thailand, few studies have discussed caregiver burden arising from performing oral care. A study from the perspective of healthcare stakeholders revealed that a lack of knowledge and skill concerning oral care, together with a high workload was stressful for caregivers.[7] Existing instruments, such as ZBI or CBI, assess general caregiver burden but do not specifically address oral care. Those tools may not comprehensively address certain challenges in delivering oral care to patients, including caregivers' aversion to oral hygiene tasks due to fear of being bitten or feelings of repulsion toward the procedure[8,9], which previously studies indicate that oral care for dependent patients involves unique challenges that may not be present in general caregiving tasks for other parts of the body.[10] Given these distinct characteristics, a specialized instrument is necessary to evaluate caregiver burden related to oral care. Consequently, we adopted the only instrument available to date, called the Oral Health related Caregiver Burden Index (OHBI) by Matsuda Y et al.,[11] to be translated into the Thai language and tested with Thai caregivers.

Thus, this study aims to develop the Thai version of the OHBI (T-OHBI) and evaluate its validity and reliability in measuring caregiver burden associated with daily oral care tasks.

Materials and Methods

The OHBI is an assessment tool, which directly measures the effect of oral health care on caregiver burden. Matsuda et al. developed OHBI to measure caregiver burden on oral hygiene care. OHBI has 5 subscales: 1) Technique-related burden (TB; questions 1, 2, 3, 6), which arises from the combination of time-dependent burden, emotional burden, and physical burden; 2) Service-related burden (SB; questions 7, 8); 3) Existential burden (EB; questions 4); 4) Risk-related burden (RB; questions 5), which has been added to this tool; and 5) Overall burden (OB). OHBI is a questionnaire with 9 questions asking about the perception of the caregiver's burden when providing oral health care with the answer on a visual analog scale ranging from 0 (never) to 4 (nearly always).[11]

The intraclass correlation coefficient, testing for reliability, yielded 0.789 as the total score (0.743 for TB, 0.779 for SB, 0.758 for EB, 0.449 for RB, and 0.842 for OB). The validity test found that Cronbach's alpha coefficient was 0.691 for SB and 0.847 for TB. The cut-off score for determining high or low caregiver burden is 10. Statistical analysis revealed a significant difference in the total score and across all factors between the high and low burden groups. In the study, developers declared the relationship between oral health-related caregiver burden and general caregiver burden, when testing the relationship between OHBI and Burden Index of caregivers (BIC-11), to be significant (r=0.620, $p<0.01$).[11]

The study was conducted in two phases. The first phase involved the translation and adaptation process to develop the Thai version of OHBI. The second phase entailed a pilot testing for reliability of the translated instrument. (Figure 1)

The sample size for face validity was twelve persons with the same characteristics as research participants based on the rule of thumb in a study by Steven A. Julious[12], Sample size calculated based on Croncach's alpha value, followed Bonett's calculation followed Bonett's (2002) method.[13] The sample size calculation was performed using the web-based Sample Size Calculator developed by Wan Nor Arifin.[14] The researchers determined the values used in the calculations as follows: expected Cronbach's alpha = 0.84 (maximum Cronbach's alpha from the original OHBI[11]). precision = 0.15 confident level = 95%, number of items = 2). The minimum target sample required in this study is forty-six. After considering a 10% non-responder rate, the minimum sample size required for this study was fifty-two caregivers. Then, it was rounded up to sixty participants.

Ethical approval was obtained from the Human Research Ethics Committee of Thammasat University

(Science) with protocol number 083/2565. The research was conducted at Thammasat University Hospital, Thailand. Participants were recruited from three outpatient clinics: 1) Dementia Clinic (Department of Psychology), 2) Dementia and Parkinson's Clinic

Figure 1: Research protocol.

(Department of Neurology), 3) Geriatric medicine clinic (Department of Internal Medicine) and 4) Gerodontology and Special Care Dentistry Clinic. The data was collected from the caregivers who were the main person responsible for the daily oral care of patients living with major neurocognitive disorders (MNDs) and Parkinson's disease (PD). We focused on community dwelling older adults for now as the majority of Thai older adults still live at home.[1] We included both informal caregivers who often were family members and live-in formal or formal caregivers. Participants were excluded if they received any oral care education interventions during the two-week study period or if the patients, they cared for passed away, experienced an acute health crisis, or required emergency treatment. However, we did not run into such conditions in this study.

Phase 1: The translation and adaptation of the OHBI

After obtaining permission from the original author, the translation process followed the "Guidelines for the Process of Cross-Cultural Adaptation of Self-Report Measures" by Dorcas *et al.,*[15] and the "Translation, Adaptation and Validation of Instruments or Scales for use in Cross-cultural Health Care Research: a Clear and User-friendly Guideline" by Sousa & Rojjanasrirat.[16]

1.1 Forward translation

The OHBI was translated from Japanese into Thai by two independent Thai-translators fluent in Japanese (JLPT Level 1 certified). To ensure comprehensive language adaptation:

• One translator had a medical background and was informed of the questionnaire's concept to provide clinical accuracy.

• The second translator, without prior knowledge of the instrument, ensured natural language use.

The two translated versions were then synthesized into an initial Thai version by a third independent translator, who resolved any discrepancies and ambiguities. For example, question number 4: "I experience hardship because caregiving does not give me a sense of satisfaction" was translated as "don't feel proud of cleaning a mouth" and "don't feel the benefits of cleaning a mouth." Each translator interpreted the phrase "sense of satisfaction" differently—one as a feeling of pride, the other as a feeling of usefulness—both of which convey distinct meanings. The third translator pointed out that the translation does not capture the core idea: that the caregiver feels the task is neither important nor worthy of their effort.
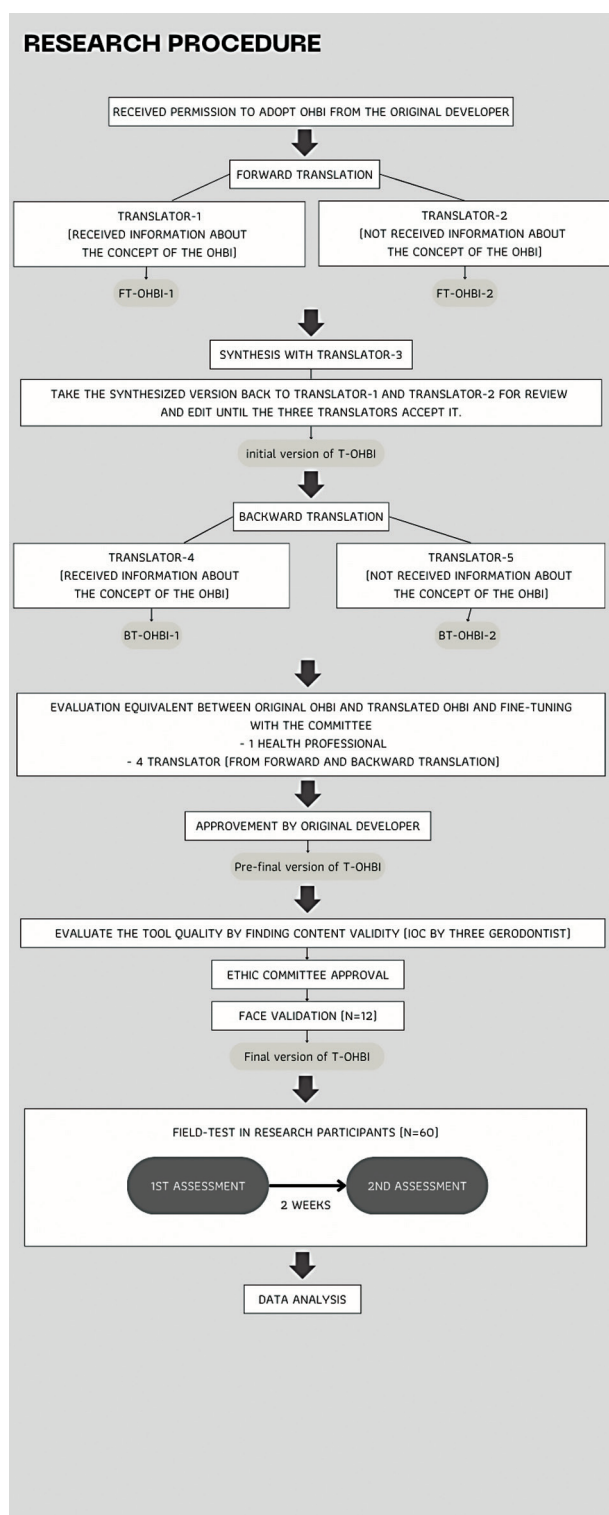
It instead emphasizes the nature of the task as lacking emotional or intrinsic value, offering no challenge, and contributing nothing meaningful to their work. Therefore, the sentence should be revised to: "Providing oral care assistance is not regarded as a meaningful task."

The revised draft was sent back to the original translators for final approval.

1.2 Back translation

To confirm that the words or sentences chosen in the initial version were appropriate, the initial Thai version of OHBI was translated back into Japanese by two independent translators who had never seen the Japanese version of the OHBI.

The translators for this back translation had the same qualifications as in the forward translation process. Two back-translated versions of the OHBI were then obtained.

1.3 Expert committee for cross-cultural equivalence consensus

In this step, a committee comprising one health professional who was a dentist with experience working in Japan and four translators from previous steps evaluated the equivalence between the original OHBI and the translated OHBI. The committee discussed the difference and similarity of the wording, sentence structure, meaning, and relevance of the instructions, questions, and responses among all versions of the translated OHBI and the original OHBI. Any ambiguity or discrepancy due to word choice or cultural aspects was adjusted. The equivalence between the original OHBI and the translated version of OHBI was achieved for "semantic, idiomatic, experiential, and conceptual equivalence" according to the protocol.[15] After a consensus had been reached, the pre-final version of OHBI was created. The back-translated of this pre-final version of OHBI was then sent to the original developer, Dr. Yuhei Matsuda, for his final approval.

1.4 Content validity assessment

The approved translated questionnaire was later evaluated by three experts in geriatric dentistry for its content validity using the index of item-objective congruence (IOC). Any part with an IOC score less than 0.5 was revised according to the experts' suggestion.

1.5 Preliminary pilot test for face validity

To evaluate if the study's target population could understand what the instrument wanted to measure, a step was conducted among twelve individual respondents in the target population. Respondents assessed comprehension of instructions, questions, and responses. Their understanding, or lack of it, was measured through questions such as "Is there any part of this questionnaire that you did not understand or found it hard to understand?" and "What do you think this questionnaire is asking you about?". After evaluating the questionnaire, the final version of the T-OHBI questionnaire was obtained. (Appendix 1).

Phase 2: Pilot-testing for the reliability and discriminant validity of the T-OHBI

Finally, the reliability and discriminant validity of the final version of T-OHBI was evaluated by sixty caregivers of patients with MNDs and PD. However, after a gentle reminder, as per the protocol, only forty-seven volunteers completed the questionnaire in week two. Data collection was done through an electronic survey platform (Google Inc., n.d.). After data collection was complete, reliability and validity tests were conducted.

Results

Content validity

The expert panel evaluated the content of the questionnaire. During the first round of evaluation, IOC scores ranged from 0.33 to 1.0. The suggestion for item modification was that this questionnaire needed to clarify whom each question was addressed to. Therefore, specific personal pronoun, "you," was added to each question. For the second round of evaluation, after the adjustment, the IOC score was 1.0 for all questions; meaning all questions in this questionnaire are considered valid and congruent with the intended purpose.

Face validity

Most participants had no difficulty understanding the instructions in the OHBI. However, one participant each had trouble reading questions 1, 4, 6, and 7, as well as one response choice. For each, there was one volunteer who expressed their opinion that they had problems reading the questionnaire. However, the questionnaire was found to be clear by more than 80% of participants in the pilot test. The majority of participants understood the questionnaire clearly. No further modification was needed.

Internal consistency

Testing for internal consistency using Cronbach's alpha found that the Cronbach's alpha coefficient of the entire questionnaire was 0.864. Cronbach's alpha value of the questionnaire on the topic of TB was 0.676, and SB

was 0.753.

Test-retest reliability

Test-retest reliability, assessed using the ICC, showed values ranging from 0.296 to 0.645, with a total score of 0.647 (Table 1).

Discriminant validity

Discriminant validity was assessed by comparing OHBI scores between caregivers with high and low burden levels, using a cut-off score of 10 points. This criterion was used to categorize participants into high and low burden groups in previous studies.[11] The Mann-Whitney U test was used to compare scores for each factor and the total score. Results indicated a statistically significant difference between groups with high and low caregiver burden. (Figure 2)

Sample characteristics

In this study, most caregivers were female (89.4%), 46.8% of the volunteers were aged sixty years, and older. For the patients under the care of volunteers, 57.4% had symptoms of MNDs, 23.4% had PD, and 19.1 % had symptoms of both diseases.

Most of the volunteers were informal caregivers (93.6%), all of whom were relatives of the patients they cared for. The remaining were informal caregivers 6.4%), of which no one had received training in patient care. Only 23.4% of all the volunteers received training in oral health care for patients (Table 2).

Results from 2nd OHBI questionnaire were presented in figure 3

Of the forty-seven participants who completed the questionnaire:

• 85.1% of participants reported experiencing some type of difficulty in providing oral care.

• Among the 47 participants, 14 (29.8%) reported difficulties in providing oral care did not necessarily perceive it as a burden.

Discussion

This study involved translating and adapting the OHBI questionnaire from the original Japanese into Thai. After passing the inspection, it was found that the T-OHBI questionnaire was equivalent to the OHBI in Japanese and could be used in the context of Thailand. The results from this study showed that Some caregiver of patient living with MNDs and PD in Thailand perceived burden from performed oral care for their care receiver.

Table 1: Test-retest reliability of T-OHBI by intraclass correlation.

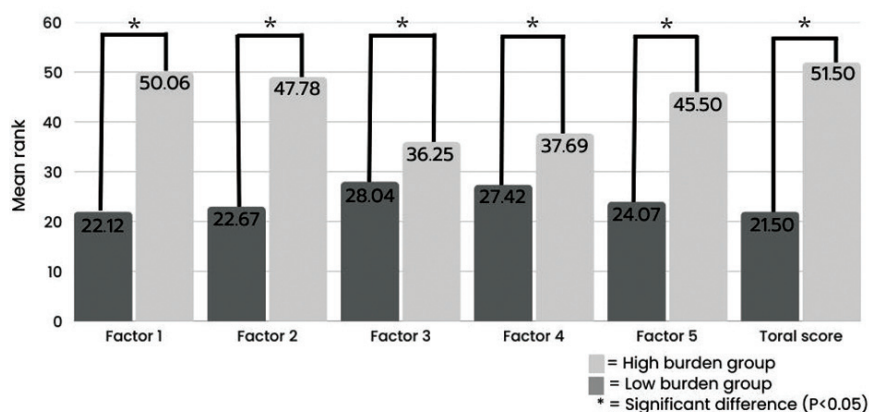|	ICC	95% CI
Factor 1: Technique-related burden (Q1, 2, 3, 6)	0.645 (moderate)	0.444-0.785
Factor 2: Service-related burden (Q7, 8)	0.580 (moderate)	0.352-0.743
Factor 3: Existential burden (Q4)	0.296 (poor)	0.023-0.531
Factor 4: Rick-related burden (Q5)	0.574 (moderate)	0.336-0.740
Factor 5: Overall burden (Q9)	0.619 (moderate)	0.408-0.768
Total score	0.647 (moderate)	0.430-0.791

Figure 2: Discriminant validity by Mann-Whitney u test (cut-off score=10).

Table 2: Characteristics of participants (N=47).

Characteristic	Number	%
Sex		
Male	5	10.6
Female	42	89.4
Age		
20-29 years	1	2.1
30-39 years	1	2.1
40-49 years	7	14.9
50-59 years	16	34.0
60 years and above	22	46.8
Type of caregiver		
Informal caregiver	44	93.6
Formal caregiver	3	6.4
Training experience of formal caregiver (n=3)		
Yes	0	0
No	3	100
Care-receiver's disease		
MNDs	27	57.4
PD	11	23.4
Both MNDs and PD	9	19.1
Experience in receiving training in oral care		
Yes	11	23.4
No	36	76.6
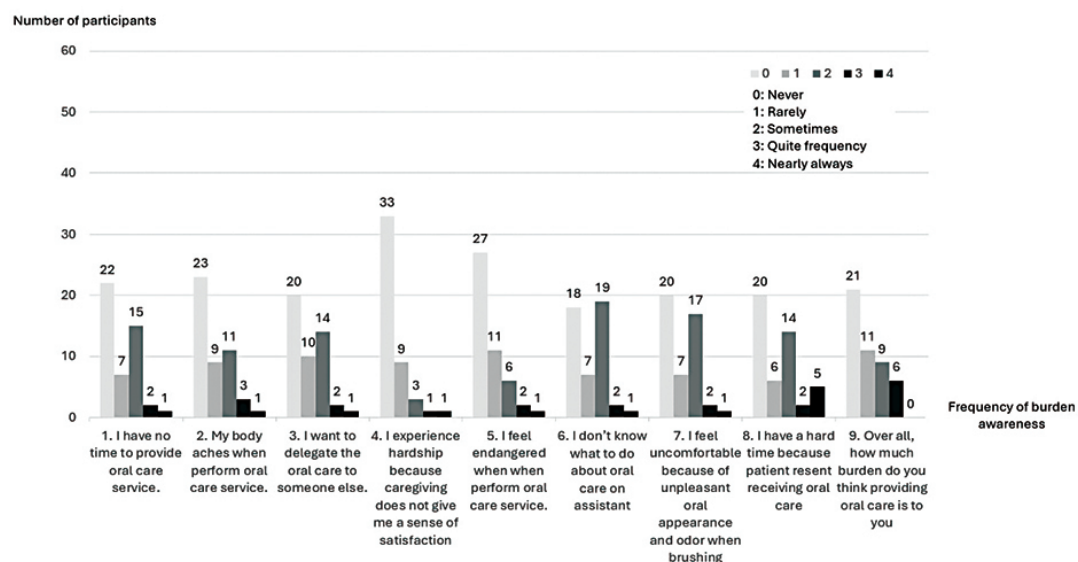
Figure 3: Results of Thai-version of OHIB from research participants (N=47).

A) Psychometric properties of a questionnaire

For psychometric properties of the questionnaire in this research, Cronbach's alpha coefficient of T-OHBI was at a good level. When compared with the test using the Japanese version of the OHBI questionnaire, The TB of the T-OHBI has a lower Cronbach's alpha coefficient. For SB, the T-OHBI has a higher Cronbach's alpha coefficient.[11]

For discriminant validity, it was found that both the original OHBI questionnaire and the Thai version had

the same result. When testing between the high-burden and low-burden groups, it was found that there were differences between the two groups in every topic in the questionnaire and total score as well.[11]

For test-retest reliability, in this study, the reliability of the existential burden of the Thai version of the questionnaire was at the poor level, which was different from the Japanese version of the questionnaire, where the factor with poor reliability was RB. Compared with the original study, this study reported lower ICC level in SB, EB, and OB but higher in RB subscale. The total score shows that the Thai version of OHBI had a lower reliability level.[11]

This study found that test-retest reliability ranged from poor to moderate levels.[17] The low ICC values may have resulted from the measurement tool's instability. The low ICC values may have resulted from the measurement tool's instability. The T-OHBI may not be suitable for evaluating the effectiveness of caregiver intervention programs, as score fluctuations could occur without an identifiable triggering event.[18]

Given that the test-retest reliability coefficient of the questionnaire fell below the acceptable threshold, it might be due to random error or systematic error.

Random error, the various unpredictable factors that interfere with the accurate measurement of a given phenomenon.[19] Respondents' emotional states may have influenced self-assessments, contributing to the low reliability of the questionnaire in this study. Changes in self-evaluation could affect the second assessment, potentially altering retest results even in the absence of an external triggering event. This phenomenon, response shift, might arise from the fact that respondents had a new conceptualization about the events in the questionnaire or a change in priorities. This could occur when there were changes in the respondent's life, such as health changes, or if the retest interval was too long.[20] Systematic error can arise from deficiencies in the measurement tool[21], the observed issue may be due to inadequacies in the questionnaire's construction, indicating potential flaws in item clarity or content.

Take repeated measurements will be necessary to confirm the property of the questionnaire. To control random errors, recollect data with an increase sample size, and utilizing a sampling strategy with greater precision will be helpful.[22] This approach allows for a clearer distinction between sample-related variability and instrument-related flaws, thereby strengthening the psychometric evaluation. If it is a random error, the results will change.[23]

B) Results from a pilot study

This study found that the most common problem caregivers encountered in providing oral care for patients was "knowledge". Slightly more than half (61.7%) of volunteers felt they did not know what to do about oral care. Secondly, we found a problem SB that includes discomfort from oral appearance and odour and had a hard time from patient's behaviour; along with the feeling of wanting to delegate their oral care duty to other people (57.4%). The results showed that most of the problems encountered by volunteers in this research were in the topic of TB and SB. This finding is in the line with the results from the previous study found that most issues in oral cleaning for patients were usually related to a lack of knowledge about oral cleaning for patients, followed by patients' resistance to oral care.[4]

In this study, there were differences in the sample groups used to assess the questionnaire between the Thai and Japanese versions. Regarding the type of caregivers, the Japanese version of the OHIB collected data from formal caregivers, while the Thai version collected data from both formal and informal caregivers. However, the number of informal caregivers in this study was 90% of the total participants. Previous studies have found that the motivation for caring is different between formal and informal caregivers in some aspects. In formal caregivers, financial factors were the main motivation for caring for the elders. Job satisfaction and whether they find caring meaningful or not played a significant role in their continual commitment to patient care.[24-26] While, for informal caregivers, cultural values and social norms were primary motivators. Whether the caregivers has a sense of reciprocity manifested from gratitude or a sense of obligation from the social belief that caring for patients is a familial duty; they accept their role of caregiving.[24,27]

The different types of caregivers between the two studies may have influenced the results. Previous studies identified the barriers to providing oral care for formal and informal caregivers. For informal caregivers, the barriers were lack of knowledge and skill in oral care. By contrast, formal caregivers also claimed a need for more training, but also cited patient resistance, lack of time, and unclear

responsibility in oral care as additional barriers.[4]

Although participants identified issues in questions 1-8 as problematic, they did not necessarily perceive them as burdensome. It may be considered that those research participants consider those problems to be stressors. We proposed that this phenomenon may be consistent with the characteristic of caregiver burden: some factors that caused the perception of that phenomenon. Having a problem with work tasks was not the only thing that caused caregivers to have a caregiver burden. Each caregiver's characteristics include sociodemographic character, background, and physical and psychological state. Environment, social support, and coping method: These factors affect the caregiver's self-evaluation of their status.[28-30] Previous studies showed that caregivers evaluate factors, and all experiences related to patient care, both positive and negative factors, to assess their condition. If negative factors do not affect the caregiver as much as positive factors, the caregiver may not recognize that they have a caregiver burden.[28]

Previous studies have identified barriers to oral care that do not appear in the OHBI questionnaire; for example, oral care equipment: both in terms of oral cleaning equipment and denture cleaning equipment[3,4,10], as well as results from a study on the oral health care status of dependent elderly people in Thailand, it was identified that those involved in oral health care for the elderly expressed the opinion that They do not have appropriate and adequate oral health care equipment for dependent elderly people. Especially among bedridden patients.[7] In addition, it was found that respecting the patient's autonomy was also considered a problem in oral cleaning for the patient.[31] Some caregivers were concerned that cleaning a patient's mouth may cause harm, such as causing bleeding.[4] There is also the issue of the relationship between individuals responsible for caring for patients.[3,10]

Various cultures and support networks across the country may lead to unique challenges faced by caregivers. Therefore, it may be necessary to consider further procedures to improve the questionnaire, such as open-ended questions to find additional problems in oral care to cover other factors that affect caregiver burden in caregivers in those areas.

Future studies may consider collecting additional information on caregivers' experiences related to caregiving, to examine their association with the level or type of caregiver burden, as well as the strategies used to cope with caregiving-related challenges.

In this study, research participants primarily consisted of elderly, female, informal caregivers. The results from this study, therefore, must be interpreted within similar characteristics of the caregivers. However, it was not an intention of the researchers to limit the inclusion but it was the real nature of the profile of caregivers at the general hospital we collected the data. Additionally, certain characteristics of the sample may affect the instrument validation. For example, older adults may experience difficulties in processing and comprehending written content[32], and it was previously reported that they tend to report higher levels of caregiver burden compared to younger age groups.[33] Some studies have shown that different types of caregivers hold differing values regarding patient care, which may lead to variations in how formal and informal caregivers perceive and interpret caregiving-related issues.[24,26,27] Future studies should consider recruiting more diverse samples, potentially through multi-centre/multi-institutional studies in multiple regions of the country. This approach may result in a sample of caregivers with greater age diversity and a higher proportion of formal caregivers. However, given the current trend in Thailand, where most elderly caregivers are female[1], expanding the data collection sites may not significantly alter the gender composition of the sample in the study.

This questionnaire will help dentists and other healthcare providers to gain a clearer understanding of the specific challenges caregivers face in providing oral care to patients. As a result, they will be better equipped to offer targeted and relevant advice or design intervention specifically fit to caregivers' actual burden. The findings from using T-OHBI will reveal if the burden comes from technical issues of oral care, which is easier to intervene or from more complicated issues such as existential crisis of the caregivers or inability to find positive meaning in caregiving or having a tendency of mental health problems. Besides helping to improve oral care for the patient, it may also help detect psychological burden of the caregivers who need further mental health assessment. The researcher suggest to establish a suitable cut-off score for the future application of this tool. This score will serve as a benchmark for directing caregivers to mental health counseling or obtaining further assistance from medical

professionals. It may also be used as a criterion for providing support to caregivers. In addition, from policy or programmatic perspectives, this questionnaire can be used as a survey tool to screen and later suggest policies that would help reduce the burden specifically from oral care related tasks.

Conclusions

The OHBI questionnaire was successfully translated and culturally adapted into Thai, demonstrating acceptable validity for the Thai population However, its reliability requires further evaluation in larger sample sizes. To enhance its effectiveness, the T-OHBI should be further refined, particularly in detecting caregiver burden factors that the current version fails to identify. This instrument is designed to assess caregiver burden related to oral care for patients with neurocognitive disorders in Thailand, facilitating the identification of burden types and informing intervention strategies to ultimately improve caregivers' quality of life.

Acknowledgment

Conflicts of Interest

The authors declare no conflicts of interest.

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