Psychometrics of a swallowing-related quality of life questionnaire:

Swallowing Activity and Participation Profile

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Abstract

The current study aimed to investigate the psychometrics of a recently developed self-reported questionnaire for swallowing related quality-of-life assessment, the Swallowing Activity and Participation Profile. This questionnaire adopted ICF framework and one consistent scale throughout the whole questionnaire to give convenience to clinicians and patients. Twenty-seven participants, including 14 non-swallowing disordered and 13 swallowing disordered, were participated in the study for the validation of the questionnaire. The results demonstrated good construct validity and convergent validity of the questionnaire. The finding suggested the questionnaire can contribute the assessment of swallowing related quality of life in geriatric populations.

Introduction

The percentage of population with age 65 or above in Hong Kong will be increased drastically from 12.8% at 2009 to 28.0% at 2039 (Census and Statistics Department., 2010), as a result health care needs in geriatric population have gained more attention than before. Swallowing disorder, which defined as difficulty in swallowing liquids, food or medication from oral cavity to esophagus (Logemann, 1998), is one of the most common disorders in geriatric population. The prevalence of swallow disorder in geriatric population were found to be from 11.4-15% in community dwelling individuals to 51-68% in institutionalized individuals (P. H. Chen, Golub, Hapner, & Johns, 2009; Holland et al., 2011; Kawashima, Motohashi, & Fujishima, 2004; Lin, Wu, Chen, Wang, & Chen, 2002; Steele, Greenwood, Ens, Robertson, & Seidman-Carlson, 1997). Physical and social effects are the common consequences of swallowing disorders (Ekberg, Hamdy, Woisard, Wuttge-Hannig, & Ortega, 2002; Marik & Kaplan, 2003). Unlike the assessment on physical aspects such as Videofluroscopy (VFSS) and Fiberoptic Endoscopic Evaluation (FEES), there are only a limited number of tools to assess the Quality-of-Life (QOL) impact of swallowing disorders. Among the published tools, all of them have certain disadvantages to prevent them from being used in clinical setting conveniently. This study is to validate recently developed self-reported questionnaire – Swallowing Activity and Participation Profile (SAPP) to serve as a convenient assessment tool to replace the current tools.

The effect of swallowing disorders can affect patients in physical, social and psychological aspects. Aspiration pneumonia, malnutrition, and dehydration are the possible physical impacts of swallowing disorder in which could be fatal (Marik & Kaplan, 2003). Beyond physical impacts, Ekberg et al. (2002) reviewed the impact of swallowing disorder on social and psychological aspects. They found mealtimes are valuable opportunity for

social communications. Individuals with swallowing disorder would have difficulties in joining such social events. Moreover, the individuals with swallowing disorder were likely to develop anxiety during mealtime, and as a result the socialization was affected. The result of the study revealed 41% of the elderly individuals living in nursing home or clinic/hospital experienced anxiety during mealtime because of swallowing disorder. Besides, 36% of the elderly individuals in that study prevented themselves from eating with others because of swallowing disorder. Since the high prevalence and serious impact of swallowing disorder were identified, many clinicians and researchers dedicated their effort in developing tools to evaluate and to treat the disability.

Recently, there are many assessment protocols and screening tools developed to symptomatically assess swallowing disorder (Bours, Speyer, Lemmens, Limburg, & de Wit, 2009; Perry & Love, 2001). In current clinical practice, Videofluroscopy (VFSS) and Fiberoptic Endoscopic Evaluation (FEES) are the gold-standard in diagnosing swallowing disorders (Rao, Brady, Chaudhuri, Donzelli, & Wesling, 2003). VFSS is an assessment make use of radiation. It requires the client to swallow food or liquid with barium in it. The x-ray machine is used to detect the food bolus dynamically during the swallow. FEES is using endoscope to monitor the swallow action at the nasopharynx. However, radiation will be required for administration of VFSS which increased the risk of health on both clinicians and patients. Both VFSS and FEES need experienced clinician to carry out. Other bedside screening protocols were therefore developed to identify patients at risk of swallowing disorder and the need for assessment (Chong, Lieu, Sitoh, Meng, & Leow, 2003; Logemann, Veis, & Colangelo, 1999). Bours et al. (2009) reviewed 11 screening protocols for detecting swallowing disorders with sufficient validity and reliability and all of them were aimed for detect the symptoms of swallowing disorders. None of them investigate the swallowing

related quality-of-life (QOL) in addition to the symptoms. The result showed the scarcity of tools on evaluating swallowing related QOL.

Assessments on quality-of-life impact subsequent to swallowing disorder were scarce. Upon the date of submission, there are only 4 validated tools aimed to assess the impact of swallowing disorder on QOL, namely M. D. Anderson Dysphagia Inventory (MDADI) (A. Y. Chen et al., 2001) , Swallow quality-of-Life Questionnaire(SWAL-QOL) (McHorney et al., 2002), Sydney Swallowing Questionnaire (SSQ) (Dwivedi et al., 2010), and Dysphagia Handicap Index (DHI) (Silbergleit, Schultz, Jacobson, Beardsley, & Johnson, 2012). However, all of them have certain inconveniences to be used in clinical settings, such as long administering time, inconsistent reporting scale, complicated scoring criteria, narrow target population, and most importantly, lack of implementation of International Classification of Functioning, Disability and Health (ICF). ICF was developed by World Health Organization. (2001) and is now the international standard to represent and qualify the health and disability. ICF included three main concepts to describe the interaction between disease and disability, which are structures and body function, activities and participation, and environmental factors. These concepts allowed us to look into the effect of diseases or disorders in a systematic framework which is important in consideration and evaluation of QOL. In the following paragraphs will introduce all published validated questionnaire to assess swallowing related QOL.

MDADI was developed by A. Y. Chen and her colleagues and published at 2001 (A. Y. Chen et al., 2001). It was the first validated self-report questionnaire to evaluate swallowing related QOL for patients with head and neck cancer. It consists of 20 questions and includes 4 subscales namely global, emotional, functional, and physical. It uses a 5-point scale to score for each question. MDADI was validated through administering the questionnaire to 100

patients with head and neck cancer. MDADI was widely used in evaluating swallowing related QOL and swallowing treatment outcomes on head and neck cancer populations (Cartmill, Cornwell, Ward, Davidson, & Porceddu, 2012; Heijnen, Speyer, Baijens, & Bogaardt, 2011; Zhen, Wang, Tao, Wang, & Chen, 2012). However, the major weakness of MDADI is that it has a complicated scoring formula in which requires much time to analyze one questionnaire. Also, during the development of MDADI, ICF developed by World Health Organization. (2001) was not implemented.

SWAL-QOL was developed by McHorney and her teammates between 2000 and 2002 (McHorney, Bricker, Kramer, et al., 2000; McHorney, Bricker, Robbins, et al., 2000; McHorney et al., 2002). It was translated to Chinese version and named Chinese version of the Swallow Quality-of-Life Questionnaire (Lam & Lai, 2011) which is the only validated tools to evaluate the swallowing related QOL in Hong Kong. SWAL-QOL has also been widely adopted in evaluating Swallowing related QOL in Netherland (Bogaardt, Speyer, Baijens, & Fokkens, 2009; Rinkel et al., 2009), France (Khaldoun, Woisard, & Verin, 2009), and Sweden (Finizia, Rudberg, Bergqvist, & Ryden, 2011). Although the SWAL-QOL was validated, the administration will be difficult for individuals who are not familiar with it for several reasons. First, the SWAL-QOL has 44 items which will take much time to finish. Second, the scoring scale throughout the whole questionnaire is not consistent and need to re-introduce the scale verbally during the administration. Moreover, SWAL-QOL was not developed under the framework of ICF.

SSQ is also a self-report questionnaire to evaluate swallowing related QOL (Dwivedi et al., 2010). It was specifically designed for patients with head and neck cancer compared with the wide target populations of SWAL-QOL and DHI. It consists of 17 questions and 2 different scoring scales in the questionnaire. Similar to SWAL-QOL, it requires

re-introduction of scoring scale when filling in the questionnaire. Despite the potential administration difficulties due to inconsistent scale, SSQ has been abundantly used in evaluating swallowing related QOL in patients with head and neck cancer (Dwivedi et al., 2012; Holland et al., 2011; Manjaly et al., 2011) ICF framework was also not introduced in this questionnaire.

DHI is the latest validated self report questionnaire aimed to evaluate QOL effect consequent to swallowing disorder (Silbergleit et al., 2012). It consists of 25 statements with 3 point frequency scale and a 7 point likert scale for the question evaluating difficulty of swallowing. It is designed for wide range of population such as patients with head and neck cancer, stroke, and Parkinson's disease. Since it is a relatively new tool, it has not been used in other studies after its validation. DHI is the only one questionnaire that included ICF framework during its development. However, the two scales in the questionnaire make it difficult to be administered. Also, the 3 point scale may not be sensitive enough for those mildly swallow disordered patient.

The Swallowing Activity and Participation Profile (SAPP; Chan, Yiu, and Ho, 2011) was therefore developed to response to the currently published self-report questionnaire by adopting consistent scoring scale throughout the whole questionnaire and shorter time requirement. It is designed to target wide range of populations such as geriatric, head-and-neck cancer, and other potential populations with risk of swallowing disorders. Also, SAPP was developed by adopting WHO's and ICF which SWAL-QOL and MDADI did not. However, the SAPP had only validated with mild-to-moderate swallowing disordered patient (Chan, Yiu, & Ho, 2011). Also, in that study, no bedside clinical assessment was given to the participants in which the study used their diet as the grouping criteria. Therefore, the current study contributed to the investigation of psychometrics of SAPP.

Therefore current study aimed to validate SAPP in geriatric population living in nursing home in order to develop a tool that is validated to evaluate the swallowing related QOL in geriatric population, especially for those living in nursing home or attending day rehabilitation center.

Materials and Methods

Participants

Thirty-Five elderly persons aged 65 years old or above living in Hong Kong were recruited from two nursing homes and one day rehabilitation center to participate in this study. Their ages are from 65 to 91 years old. Eight of them were unable to finish the questionnaires due to different reasons, such as aphasia or dementia. Therefore, 27 participants were included into the study. The 27 participants were then differentiated into two groups – swallowing disordered group and non-swallowing disordered group by a screening procedure. The demographic is summarized in table 1 below.

Table 1 Demographic data of participants

Medical background	Number	Percentage
Stroke	12	44%
Parkinson's disease	3	11%
Alzheimer's disease	5	18.5%
Stroke and Parkinson's disease	2	7.4%
Stroke and Parkinson's disease and Alzheimer's disease	1	3.7%
No swallowing related history	4	14.8%
Total	27	

Procedures

The participants were given the SAPP (See Appendix A), and the MDADI (See Appendix B) to complete via verbal instruction from researchers. Tongue peak pressure measurement, oral motor examination and trial swallow were used to determine the existence of swallowing disorder in the participants. To ensure the task effect is balanced, the order of

of the tasks was randomized. After three weeks, the SAPP was given to six of the participants again in order to determine the test-retest reliability.

The Swallowing Activity and Participation Profile (SAPP)

The SAPP (See Appendix A) was developed by Chan, Yiu, and Ho (2011). The SAPP is a self-report questionnaire designed to evaluate the effect of swallowing disorders on quality of life (QOL) of patients. SAPP was developed by adopting the ICF framework, with concepts including impairment, activity limitation, and participation restrictions. The SAPP consists of five sections including a) Medical history and current diet, b) swallowing functions, c) swallowing problems on the personal domain, d) swallowing problems on the social and occupational domain, and e) swallowing problems on the emotional domain. The factual information, such as the age, gender, feeding options, and recent history of pneumonia, were obtained in section one. Thirty-four questions with a consistent 10-point likert scale consisted the other four sections.

M. D. Anderson Dysphagia Inventory

MDADI was developed by A. Y. Chen et al. (2001). It is a standardized self-report questionnaire designed to investigate effect of swallowing disorder on the quality of life (QOL). Despite the initial standardizing population was head and neck cancer patient (A. Y. Chen et al., 2001), it was adopted in study targeting general geriatric patients (P. H. Chen et al., 2009). The MDADI consists of three subscales to evaluate the QOL, which are emotional, functional, and physical scales. In this study, the Cantonese version of MDADI was used to evaluate the convergent validity.

Iowa Oral Performance Instrument (IOPI)

IOPI is a non-invasive tool to measure the lingual pressure (Robbins, Levine, Wood, Roecker, & Luschei, 1995). As the lingual pressure showed to be a predictor of swallowing

disorder, the IOPI is now used in screening of swallowing disorder (Stierwalt & Youmans, 2007). Norm data for IOPI to determine swallowing disorders was developed in United States of America in preschool, adolescent, adult, and geriatrics population (Potter & Short, 2009; Youmans, Youmans, & Stierwalt, 2009). The IOPI will be used in determining construct validity of the SAPP and the cut-off score will be set at 40.69 kPa which is 1SD lower than the mean of normal group with age 60 to 91.

Swallowing Screening Procedures

The swallowing screening procedures is to rate the severity of swallowing disorders in the participants. The participants were asked to swallow three times on each kind of food including crackers, water, and orange juice. To decide which set of food to be tried, the diet of the participants was known before. If the diet of the participant is modified, he/she was first given orange juice thickened to medium thick texture. Mildly thick, thin, or ultimately a piece of cracker was given to the participant if he/she was able to swallow the food of previous level without any signs of swallowing disorder such as coughing, choking, throat clearing. The trial swallow was terminated when signs of swallowing disorders appeared such as coughing and throat clearing. The whole procedure of trial swallow was supervised by an experienced speech therapist.

The participants were rated as normal, mildly swallowing disordered, moderately swallowing disordered, and severe swallowing disordered according to the results of swallowing screening procedure. Participants needed to pass all trial swallow in order to be rated as normal. If the participants could not pass in any trial in swallowing a piece of cracker, he/she was regarded as in mildly swallowing disordered group. If the participants failed to swallow thin liquids, the participant was rated to be moderately swallowing disordered. If the participant failed any trials in thickened liquid, he/she will be grouped into severely

swallowing disordered group.

Data Analysis

In this study, test-retest reliability, construct validity and convergent validity of SAPP will be determined by statistical method. To determine test-retest reliability, the *Spearman's rho* between the two measures of SAPP was found. It investigated the correlation of the two measures of SAPP separated by three weeks. The scores in all the sessions and the total score were brought to the statistical analysis. Since the number of participants is small, *Spearman's rho* was used. To determine the construct validity, the method of known-groups measure was used. Tongue peak pressure measurement (Robbins et al., 1995) were used in determining non-swallowing disordered group and swallowing disordered groups. Construct validity were determined by the extent of the differences of scores in SAPP which indicated by *independent t-test*. The MDADI (A. Y. Chen et al., 2001) was used to determined the convergent validity by investigating the correlation of score between it and the SAPP. The correlation was determined by *Pearson's r.*

Result

Data Analysis

Based on swallowing screening, eight participants were rated to be swallowing disordered while 14 were rated to be swallowing disordered by Tongue peak pressure measurement. (See table 2). The descriptive statistics of Swallowing Activity and Participation Profile (SAPP) and M. D. Anderson Dysphagia Inventory (MDADI) were summarized in Table 3. The mean, standard deviation, minimum, and maximum of each section for SAPP and MDADI were included. The summary of each question was summarized in table 4.

Test retest reliability

The results are summarized in Table 5. The total score showed no significant correlation (n=6, ρ=0.486, p>0.05, one-tailed) between the two measures separated by three weeks.

Table 2 Minimum, maximum, means, and standard deviation of SAPP results in group defined by Swallowing screening

	Non-swallowing disordered group (n=19)				Mild swallowing disordered group (n=4)			
SAPP	Min	Max	Mean	SD	Min	Max	Mean	SD
Swallowing Fx.	0	32	7.53	9.11	3	22	10.25	9.14
Personal	0	40	5.05	11.16	0	0	0	0
Social & Occu.	0	28	2.58	6.84	0	0	0	0
Emotional	0	29	3.32	7.88	0	2	0.5	1
Total	0	92	18.47	30.70	3	22	10.75	9.39
	Moderate swallowing disordered group (n=3)				Severe swallowing disordered group (n=1)			
SAPP	Min	Max	Mean	SD	Value			
Swallowing Fx	2	16	8.33	7.09	33			
Personal	0	24	8	13.86	40			
Social & Occu.	0	0	0	0	30			
Emotional	0	26	8.67	15.01	19			
Total	2	66	25	35.59	122			

Construct Validity

Tongue peak pressure measurement was used to determining the known-group by adopting the cut-off, 40.69, from Youmans et al. (2009), the number of participants in swallowing disordered group is 13 while the other is 14. The result was summarized in Table 6. It is found that the four sections except social and occupational section were significantly different between groups. Moreover, the total score was also found to be significantly different between groups ($t=-3.180$, $p<0.05$)

Table 3 Descriptive statistics of SAPP and MDADI results in known group defined by Tongue peak pressure measurement

	Swallowing-disordered Group (n=13)				Non-swallowing disordered group (n=14)			
MDADI*	Min	Max	Mean	SD	Min	Max	Mean	SD
Emotion	20.83	100	76.60	25.03	20.83	100	89.55	20.10
Function	35	100	75.00	21.79	35	100	82.11	17.18
Physical	28.12	100	71.15	23.11	18.12	100	77.14	19.93
Total	27.50	100	74.03	21.85	27.5	100	80.53	18.14
SAPP	Min	Max	Mean	SD	Min	Max	Mean	SD
Swallowing Fx.	0	33	14.46	10.68	0	15	3.86	5.14
Personal	0	40	12.07	15.81	0	2	0.21	0.58
Social & Occu.	0	30	5.85	10.87	0	2	0.21	0.58
Emotional	0	29	8.23	11.11	0	2	0.21	0.58
Total	0	122	40.62	42.25	0	15	4.5	4.97

* Higher mark indicates good functioning, emotion, and physical condition

Table 4 Descriptive statistics of each questions in SAPP

Question number	Minimum	Maximum	Mean	Std. deviation
5	0	10	1.074	2.541
6	0	7	0.630	1.621
7	0	9	1.667	2.287
8	0	8	1.519	2.190
9	0	1	0.074	0.267
10	0	5	0.667	1.468
11	0	6	0.370	1.245
12	0	5	1.000	1.529
13	0	8	1.037	2.066
14	0	6	0.926	1.940
15	0	10	1.333	2.617
16	0	4	0.185	0.786

17	0	9	0.593	1.966
18	0	8	0.519	1.748
19	0	10	0.593	2.062
20	0	10	0.556	2.006
21	0	10	0.482	1.988
22	0	10	0.519	1.988
23	0	10	0.593	2.117
24	0	10	0.556	2.118
25	0	10	1.074	2.800
26	0	2	0.148	0.534
27	0	10	0.741	2.669
28	0	10	0.556	2.118
29	0	5	0.259	0.984
30	0	1	0.074	0.269
31	0	2	0.074	0.385
32	0	0	0.000	0.000
33	0	0	0.000	0.000
34	0	10	1.407	3.016
35	0	5	0.556	1.601
36	0	6	0.593	1.716
37	0	6	0.593	1.575
38	0	8	0.926	2.235

Convergent Validity

The result was summarized in Table 7. The total score of both questionnaire were found to be significantly correlated ($r=-0.791$, $p<0.01$, 2-tailed). Also, the swallowing section in SAPP was found to be significantly correlated with physical section in MDADI ($r=-0.668$, $p<0.01$, 2-tailed). Personal section of SAPP was found to be significantly correlates with Functional section in MDADI ($r=-0.824$, $p<0.01$, 2-tailed). Emotional section of SAPP was found to be significantly correlates with Emotional section of MDADI ($r=-0.869$, $p<0.01$, 2-tailed) in which considered to be corresponding part in both questionnaire. Social and Occupational section was not correlated with any part of MDADI since there is no

corresponding part.

Table 5 Test-retest reliability found by Spearman's rho in SAPP

	No. of subjects	Spearman ρ	Significance
Total	6	0.486	0.164

Table 6 Independent t-test for the total and sections score of SAPP between swallowing disordered group and non-swallowing disordered group defined by Tongue peak pressure measurement result

	Independent t-test		
SAPP	t	df	Significance(2-tailed)
Swallowing Fx.	-3.326	25	0.003*
Personal	-2.809	25	0.010*
Social & Occupational	-1.937	25	0.064
Emotional	-2.699	25	0.012*
Total	-3.180	25	0.004*

Significant difference at 0.05 level (2-tailed)

Table 7 *Pearson's r* for the total and sections score of the SAPP and total scores and subscales of MDADI

		SAPP				
		Total scores	Swallowing Fx.	Personal	Social & Occu.	Emotional
MDADI	Total scores	-0.791***				
	Physical		-0.668***			
	Functional			-0.824***		
	Emotional					-0.869***
	Global					

**Significant correlation at 0.01 level (2-tailed)

Discussion

Reliability and Validity of Swallowing Activity and Participation Profile

The test of face validity was completed in Chan, Yiu, and Ho (2011). To further investigate the psychometrics of the SAPP, the test-retest reliability, construct validity, and convergent validity were evaluated through statistical methods.

Test-retest reliability. The test-retest reliability was evaluated by correlating the scores of SAPP in two data collections with 3 weeks separations. *Spearman's rho* was implemented and revealed no significant correlation (See Table 1). The findings may reveal the difficulties in developing reliable tools to evaluate swallowing related QOL in geriatric population. Some underlying cognitive impairment, such as dementia, may hinder client to reliably fill in the questionnaire according to their current feelings and situations. However, within the six participants, there is one participants appeared to be relatively weak compared to the previous measures three weeks before. That may contribute to the deviances between two times of measures. Despite the insignificant correlation shown, the very small size of subject made this statement not convincing. To further check with the test-retest reliability of SAPP, more participants are needed to be included in the further studies.

Construct validity. Known group design was implemented to investigate the construct validity of SAPP. Tongue peak pressure measurement (IOPI) was implemented to define the known groups. The Tongue peak pressure measurement, which evaluates the tongue strength, is a predictor to evaluate participants' swallowing ability as the tongue strength did not change upon different food or apparatus presented. The SAPP has been found to have construct validity in geriatric populations especially whom lives in nursing home or attending daily rehabilitation centers. Among the four sections of SAPP, the three sections apart from Social and Occupational section were found to be significantly different in the two known

groups. The Social and Occupational section were found to be insignificantly different, which could be accounted by the decreased range of distribution. In questions 32 and 33 which asked the impacts of swallowing disorders on their work and income, all the 27 participants rated zero since they do not have work at all. In other questions in Social and Occupational sections, six out of nine questions have standard deviation lower than one compared with the total eight questions lower than one standard deviation throughout the whole questionnaire. As the Social and Occupational section is aimed to evaluate the participation restriction defined in ICF framework, the effect of swallowing disorder on participation restriction in the participants would be highly depended on the environment factors and their needs of participation. In the current study, the participants are residents in nursing homes. They may not have much participation in work and social events compared with other population such as adults with head and neck cancer which evaluated in other studies. The effect is therefore diminished in the current study. The distribution range of score in Social and occupational section in SAPP is therefore diminished. In further research, the two questions may need to be deleted or modified in order to achieve better representation of participants' situation in Social and Occupational if the participants did not have any work. Moreover, to better evaluate the questionnaire, especially the Social and Occupational section, population with more participation such as younger patients with head and neck cancer, may be better for evaluating such domain.

As tongue peak pressure measurement cannot determine the severity of swallowing disorder because no study was done to investigate this function, no information could be obtained on the ability to differentiate geriatric individuals with SAPP. This result reveals that SAPP is a tool with construct validity, which is to differentiate patients who are at risk of swallowing disorders from who without such risk. This is important for clinical use which

will be stated in the later part.

Convergent validity. *Pearson's r* was implemented to investigate the convergent of validity of SAPP to the MDADI, which is one of the validated tools to evaluate swallowing related QOL. The result revealed the total score of SAPP has a significant correlation with the total score of MDADI (See table 5). This result found the SAPP has convergent validity with MDADI. This result echoes the findings in Chan, Yiu, and Ho (2011). It implies SAPP can also be used in populations that MDADI now targeting. In the statistical findings in correlating different part of SAPP and MDADI, most of the parts were found to be significantly correlated to the corresponding part. For example, the swallowing section is significantly correlated to physical part of MDADI which is considered as the corresponding section. The Social and occupational section of SAPP was not correlated with any part of the MDADI.

Strengths of Swallowing Activity and Participation Profile. Swallowing Activity and Participation Profile (SAPP) has overcome disadvantages that shown in other published questionnaires. SAPP has a consistent rating scale so that the clinician or other health professionals who administer the test do not need to introduce another scale in the midway of the questionnaire compared to SWAL-QOL, MDADI, and DHI. The patients also need one less time to adapt to the scale. This features allowed quick administration of SAPP compared with other questionnaire since introducing rating scales to geriatric population takes much time. Also, the SAPP is able to allow clinicians to look into the effects of swallowing disorder in different domains easily since the questions are separated in different parts of the questionnaire unlike MDADI. Further, SAPP allowed thorough evaluation of the effect of swallowing disorder in different domain in ICF framework. This enables clinicians to view the swallowing disorder from broader viewpoints.

Limitations and further research areas

In the current study, only 80% of the recruited participants could finish the questionnaire upon researchers' verbal instruction and explanation. This difficulty in recruitment of participants is because in our study, among participants who have swallowing disordered, many of them have history of stroke or dementia. As stroke and dementia can depress individual's communication ability, the SAPP which having a 10 point likert-scale would be too difficult for this group of geriatric population. To improve, we may take two directions. First, to simplify the rating scale may allow individuals with more cognitive deficit finish the questionnaire. Dysphagia Handicap Index (DHI) is an example (Silbergleit et al., 2012). DHI is a questionnaire with 3 ratings for each item which are never, sometimes, and always. As DHI is a validated questionnaire in evaluating the swallowing related QOL in patients with different etiologies including stroke, it is believed this modification could fulfill the need of change. However, the DHI was not validated with participants with Parkinson's disease, Alzheimer's disease, or other type of disease that could cause dementia. Therefore, this modification may not be enough to help the patients with dementia. Another way to modify the questionnaire may be to develop a Parent / Caregiver version of SAPP. This way of modification was found in another study evaluating the childhood swallowing ability before and after tonsillectomy which considered as treatment of swallowing disorder (Clayburgh et al., 2011). In that study, parents of the children were invited to fill in a modified version of SWAL-QOL in order to evaluate the treatment outcome of the tonsillectomy. Although the modified version was not validated, it shed lights on the way to improve the assessment on swallowing related QOL in geriatric populations. In further research, the SAPP could be modified into caregiver version so that the participant with limited cognitive ability and/or communicative ability could also enroll in the assessment of swallowing related QOL. In this

possible further study, the time spent by and the type of caregivers may give different results. It is because the closer caregiver may be able to give more accurate information. Also, if the caregiver is relative of the participant, for example son or daughter, may pay more attention on the participant's swallowing ability.

The current study reviews only the possibility of face-to-face interview. To further enhance the use of SAPP in more convenient way, the adaptation of SAPP in mailing could be one of the further research areas. To achieve the goal, modification may be required. It is because in the current study most of the participants require verbal presentation of the items. In other words, they cannot finish the questionnaire independent from a health professional in which it makes the purpose of simple swallowing screening unmet. To improve, computer-based system may be required to verbally present the questions, and an easy touch response system could be included to reduce the difficulty. Moreover, simple manual can be designed to let other health professional to administer the questionnaire in order to maximize the use of SAPP.

To ensure the validity of SAPP in population with other etiologies such as head and neck cancer, Parkinson's disease, gastroesophageal reflux disease (GERD), and more, validation of SAPP could be done in these populations. Also, as in the current study, we have used tongue peak pressure measurement as the criterion in defining swallowing disordered group. Since tongue peak pressure measurement was an screening tool only, the defined group may not be as accurate as other validation studies (Lam & Lai, 2011; Silbergleit et al., 2012) which using VFSS and hospital record to define the group. Therefore in the further study, the research project can be cooperated with hospital so that a more accurate record of swallowing ability can be obtained.

Clinical Implications

After the validation of SAPP, the tools can now be used in three areas. The three areas are evaluating swallowing related QOL, monitoring treatment outcomes, and screening patients with swallowing disorder.

First, the tool can serve as a reliable tool to evaluate the swallowing related QOL quickly. After knowing the swallowing related QOL, the clinicians could have a clear picture on the patient's swallowing ability and design more suitable treatment approach to the patient. This may also help in prioritizing treatment goals as the treatment can be individualized to the area that affected the patients most.

Second, the tool can serve a mean to monitor the treatment outcome. As it is quick to be administered, the questionnaire can be done every several weeks to monitor the ongoing treatment. Comparing the SAPP with the other assessment tools, the SAPP is quick to finish which can save time to screen out patients who need further assessment. Moreover, it does not require health professional at the time of administration which saves manpower. Also, it does not require radiation which poses less threat to both the clinicians and patients. In the other way, comparing with screening tools such as bedside swallowing screening, it provided a quantified way to evaluate the treatment outcome. Also, it reflects the swallowing ability representatively since it evaluates the whole process of swallowing disorder including its social, personal, and emotional effect. In comparison, the swallowing screening cannot give quantified information but subjective impressions only.

Third, the SAPP can act as a screening tool for patients who do not know whether they have swallowing disorder. As more individuals reached age 65 (Census and Statistics Department., 2010), the need for screening of swallowing disorder is important since we don't have to implement much manpower in assessing all the geriatric populations. Besides, as we find from studies in other country, the prevalence of swallowing disorder is not low, the

screening is important for allocating resources to those who need extra care and treatment for their swallowing disorder.

Conclusion

In the current study, the Swallowing Activity and Participation Profile was validated to be a questionnaire to evaluate the Quality of life in patients with swallowing disorders. Construct validity, convergent validity was found to be existent in SAPP. Test-retest reliability was found to be requiring further examination with more participants. Other from Quality of life, SAPP can serve as a screening tool to identify patients with needs of further assessment. The SAPP can also serve as monitor for treatment outcomes in advantage with its quick administration time.

Acknowledgements

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Appendix A

「吞嚥活動及參與量表」

“Swallowing Activity & Participation Profile-SAPP”

此問卷關於閣下的吞嚥情況及吞嚥問題對閣下的影響
問卷分為五部份，包括：
一、 基本個人資料
二、 吞嚥情況
三、 吞嚥問題對個人的影響
四、 吞嚥問題對社交及工作的影響
五、 吞嚥問題對情緒的影響

This questionnaire relates to your swallowing and how swallowing problems affect your quality of life.
The questionnaire is divided into 5 sections.
A. Background
B. Swallowing Impairment
C. Swallowing problems in personal domain
D. Swallowing problems in social and working domain
E. Swallowing problems in emotional domain

一.基本個人資料 Background

*請在適當的 ☐ 打 ✓

* Please put a ✓ in the appropriate boxes.

姓名/ Name:_____

年齡/ Age: _____

姓別:☐ 1 男 ☐ 2 女

Gender:☐ 1M ☐ 2F

1.你現時有沒有用鼻管或胃管餵食?

Are you using tube feeding now?

☐ 1 有 (請到第 1.1 題)　　☐ 0 沒有(請到第 2 題)

1 Yes (please go to question. 1.1)　　0 No (please go to question. 2)

如現時有用鼻管或胃管餵食，

If you are using tube feeding now,

1.1 你用了多長時間?　　___天 或___星期 或____月

How long have you been using it for?　__days/__weeks/_months

2.你有沒有曾經用過鼻管或胃管餵食?

Did you use tube feeding before?

☐ 1 有 (請到第 2.1 及 2.2 題)　　☐ 0 沒有(請到第 3 題)

1 Yes (please go to question. 2.1 &2.2)　　0 No (please go to question 3)

如曾經用過鼻管或胃管餵食，

If you used tube feeding before,

2.1 你最近一次在甚麼時候用過? _____年_____月

When was the last time you used tube feeding? Month/Year:_____

2.2 你用了多長時間? ____天 或___星期 或____月

How long did you use it for? ___days/___weeks/__months

3. 過去十二個月，你有否患上過肺炎?

In the past 12 months, did you catch pneumonia?

☐ 1 有 (請到第 3.1 及 3.2 題)　　☐ 0 沒有 (請到第 4 題)

1 Yes (please go to question 3.1 &3.2)　　0 No (please go to question 4)

如在過去十二個月內有患上過肺炎，

If you had pneumonia in the past 12 months,

3.1 你總共患上過多少次肺炎? _____次

How many times of pneumonia did you catch?_____Times

3.2 最近一次患上肺炎是甚麼時候? _____年_____月

When was the last time you had pneumonia? Month/Year:____

4. 你現時有沒有用口進食? Do you now eat orally?

☐ 1 有 (請到第 4.1, 至 4.4 題)　　☐ 0 沒有請到第 15 題)

1 Yes (please go to question 4.1 to 4.4)　　0 No (please go to question 15)

如你現在有用口進食，你現在最常進食的是? If you eat orally, what kind of food do you take most of the time?

4.1 飯(只選一項):

Rice(please select one only):

☐ 1 正常飯　☐ 2 軟飯　☐ 3 飯糊(包括粥)　☐ 4 湯飯

☐ 1 Normal rice　☐ 2 Soft rice　☐ 3 Porridge/ congee　☐ 4 Soup based rice

4.2 肉(只選一項):

Meat (please select one only):

☐ 1 一般肉塊/肉片 ☐ 2 肉絲 ☐ 3 肉碎 ☐ 4 經攪拌處理的肉糊

☐ 1 Normal meat slices ☐ 2 Shredded meat ☐ 3 minced meat ☐ 4 Blended meat puree

4.3 菜(只選一項):

Vegetbale(please select one only):

☐ 1 一般菜塊 ☐ 2 菜絲 ☐ 3 菜碎 ☐ 4 經攪拌處理的菜糊

☐ 1 Normal vegetable slices ☐ 2 Shredded vegetable ☐ 3 minced vegetable ☐ 4 Blended vegetable puree

4.4 飲品(只選一項):

Drinks(please select one only):

☐ 0 一般正常飲品(如水，果汁，湯，牛奶等)

0 Normal drinks (e.g. water, orange juice, soup, milk)

☐ 必須加入凝固粉的飲品 (約每一杯水加入_____標準茶匙凝固粉)

Drinks with thickener (approximately____ teaspoon(s) per cup of water)

二. 吞嚥情況 Swallowing Impairment

請回答以下有關吞嚥的問題。

Please answer the following questions concerning your swallowing situation.

5. 你現在吃固體食物時，會否感到困難？

Do you have problems eating solid food?

沒有	○	○	○	○	○	○	○	○	○	○	○	經常
No	0	1	2	3	4	5	6	7	8	9	10	Always

6. 你現在喝流質飲料時，會否感到困難？

Do you have problems drinking liquid?

沒有	○	○	○	○	○	○	○	○	○	○	○	經常
No	0	1	2	3	4	5	6	7	8	9	10	Always

7. 你現在吃固體食物時，會否咳?

Do you cough when you eat solid food?

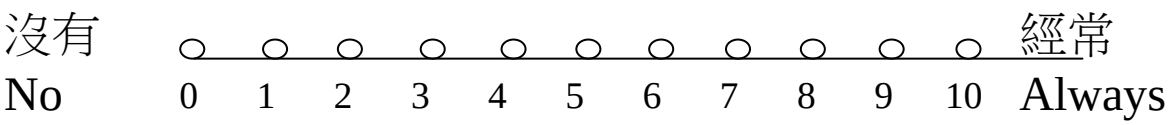
沒有	○	○	○	○	○	○	○	○	○	○	○	經常
No	0	1	2	3	4	5	6	7	8	9	10	Always

8. 你現在喝流質飲料時，會否咳?

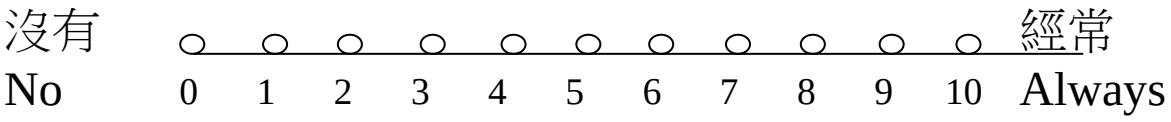
Do you cough when you drink?

沒有	○	○	○	○	○	○	○	○	○	○	○	經常
No	0	1	2	3	4	5	6	7	8	9	10	Always

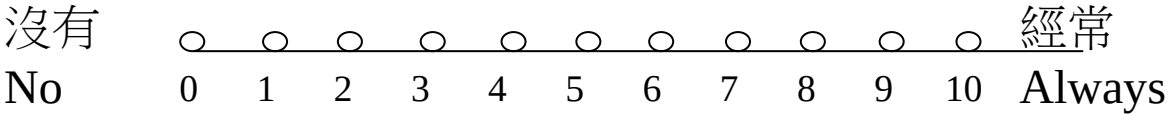
9. 你現在吃固體食物時，食物會否走進鼻內？
Does the food get into your nose when you eat?



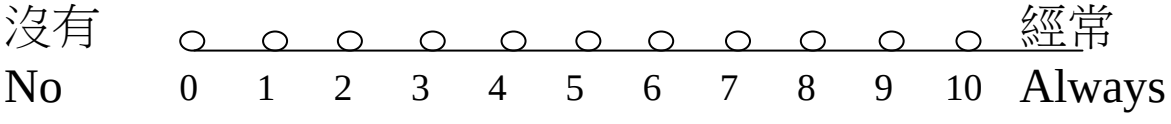
10. 你現在吃固體食物時，食物會否從口腔溜出？
Does the food drop out from your month when you eat?



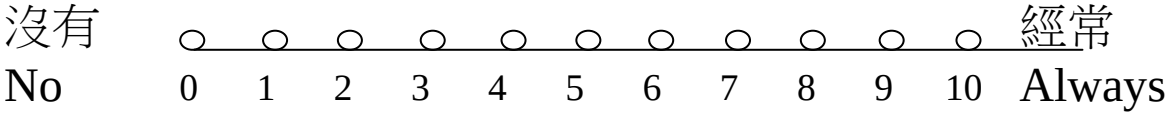
11. 你現在喝流質飲料時，飲料會否流進鼻內？
Does the liquid get into your nose when you drink?



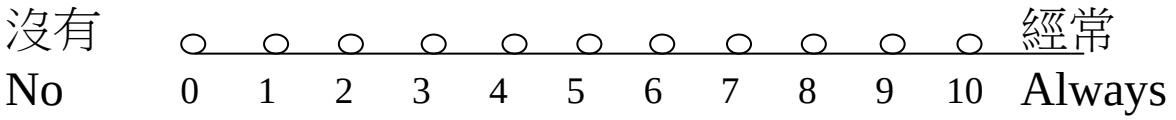
12. 你現在喝流質飲料時，飲料會否從口腔溜出？
Does the liquid leak from your mouth when you drink liquid?



13. 你現在進食後，會否感到喉嚨黏有東西？
Does the food stick in your throat after swallowing?

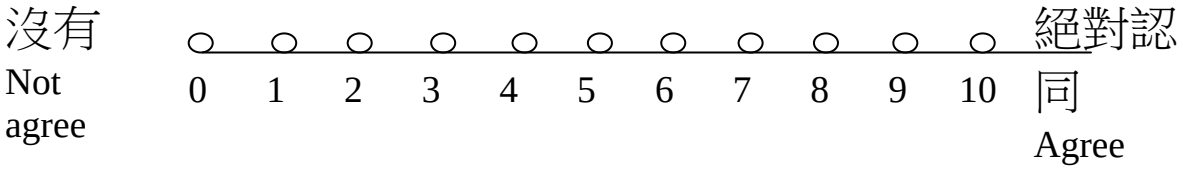


14.你現在進食後，會否感到口中黏有東西？
Does the food stick in your mouth after swallowing?

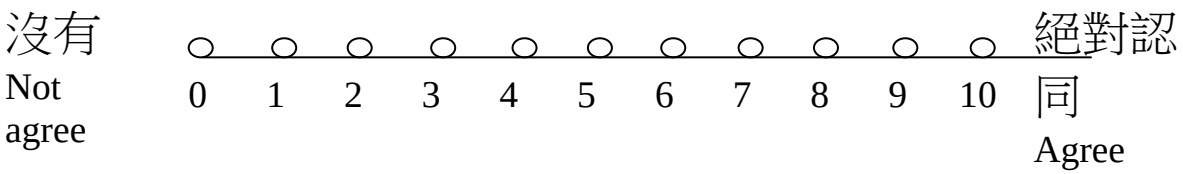


三.個人影響 Personal domain

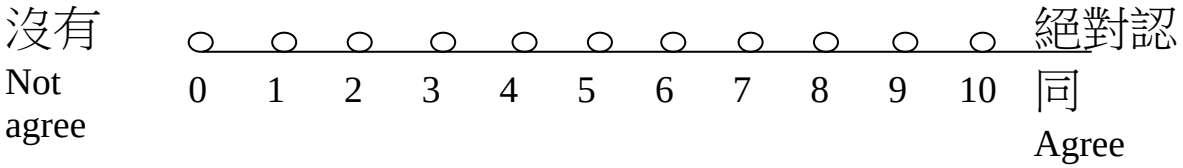
15.吞嚥問題增加了我每餐的進食時間。
Swallowing problems increase my meal time.



16.在過去一個月，我因吞嚥問題選擇減少每天進食的餐數。
In the last month, I chose to reduce the total number of meals each day because of my swallowing problems.

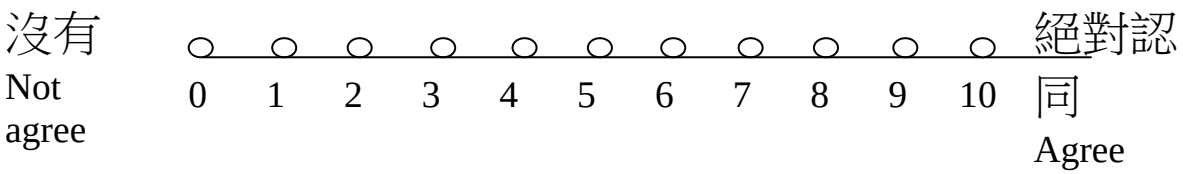


17.吞嚥問題令我不能吃太多份量的食物。
Swallowing problems reduces the amount of food that I can take in each meal.



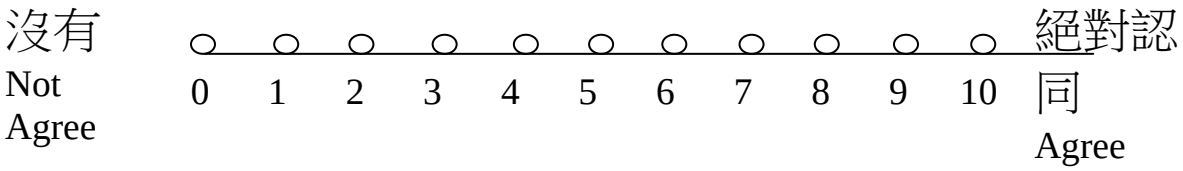
18.在過去一個月，我因吞嚥問題選擇減少每餐進食的份量。

In the last month, I chose to reduce the amount of food or drinks in each meal due to my swallowing problems.



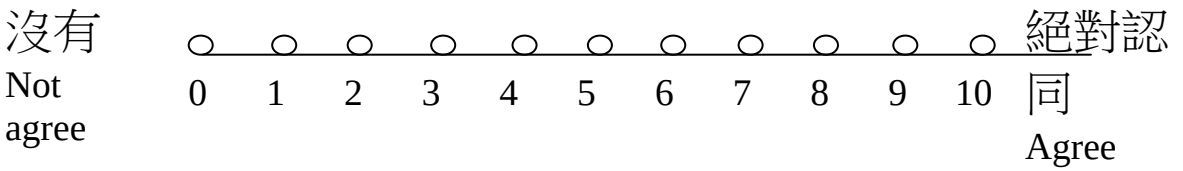
19.吞嚥問題令我不能吃我喜歡的食物或飲料。

Swallowing problems stop me from taking food or drinks that I like.



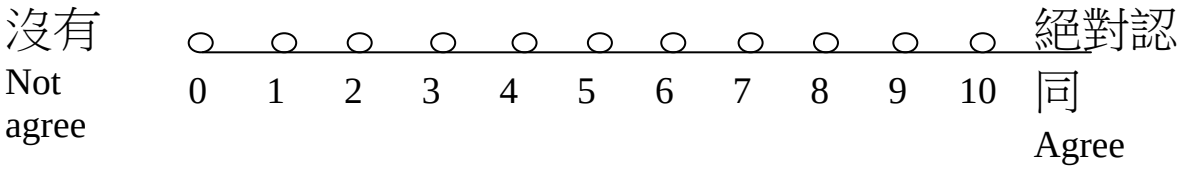
20.在過去一個月，我因吞嚥問題選擇減少吃我喜歡的食物或飲料。

In the last month, I chose to reduce taking food or drinks that I like due to my swallowing problems.

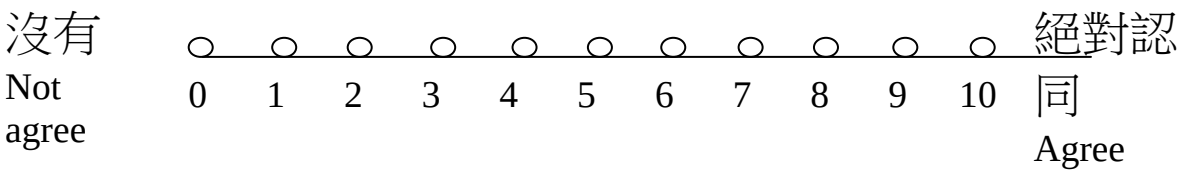


21.吞嚥問題限制了我吃食肆烹調的食物。

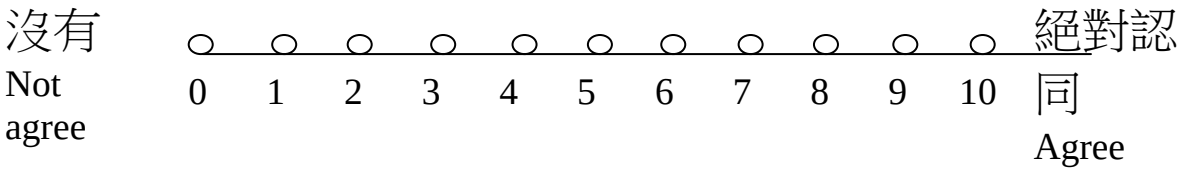
Swallowing problems limit my ability in eating food cooked in the restaurants.



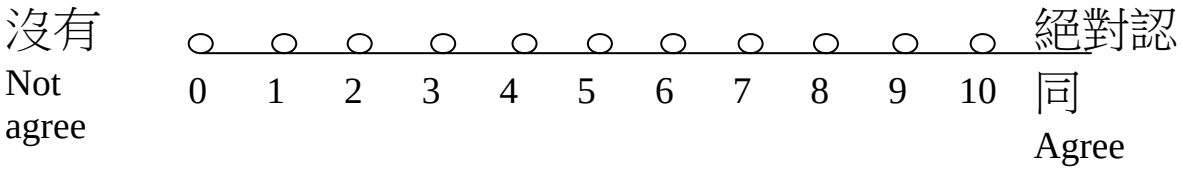
22.在過去一個月，我因吞嚥問題選擇減少外出吃飯。
In the last month, I chose to dine out less frequent due to my swallowing problems.



23.吞嚥問題增加了我的經濟負擔。
Swallowing problems cause my financial hardship.



24.在過去一個月，我因為吞嚥問題所造成的經濟負擔而選擇減少其它消費(例如: 減少買東西或外出消遣)。
In the last month, I had to reduce my general expenditures (e.g. shopping and entertainment) due to the increased financial burden brought about by my swallowing problems.



四.社交(家人，朋友)及工作影響
Social (family and friends) & working domain

25.家人因為我的吞嚥問題表現困擾。

My family is disturbed by my swallowing problems.

沒有 Not agree	0	1	2	3	4	5	6	7	8	9	10	絕對認同 Agree

26.在過去一個月，吞嚥問題影響了我和家人的交往。

In the last month, my interaction with my family was affected by my swallowing problems.

沒有 Not agree	0	1	2	3	4	5	6	7	8	9	10	絕對認同 Agree

27.朋友因為我的吞嚥問題表現困擾。

My friends are annoyed by my swallowing problems.

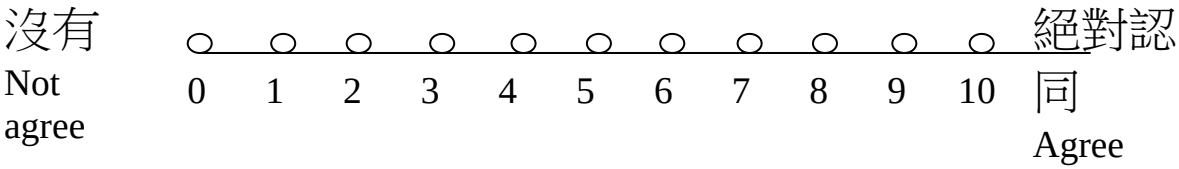
沒有 Not agree	0	1	2	3	4	5	6	7	8	9	10	絕對認同 Agree

28.在過去一個月，吞嚥問題影響了我和朋友的交往。

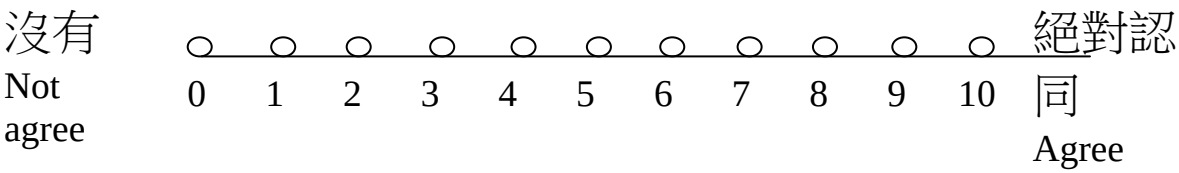
In the last month, social interaction with my friends was affected by my swallowing problems.

沒有 Not agree	0	1	2	3	4	5	6	7	8	9	10	絕對認同 Agree

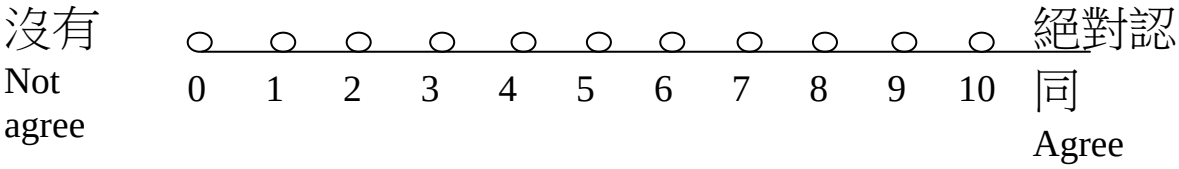
29.吞嚥問題影響了我跟家人一起吃飯。
Swallowing problems affect dining together with my family.



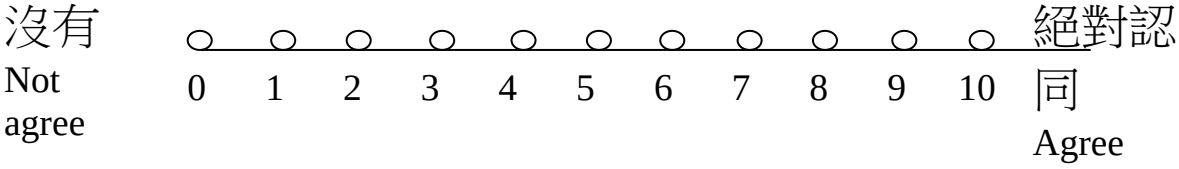
30.吞嚥問題影響了我跟朋友一起吃飯。
Swallowing problems affect dining together with my friends.



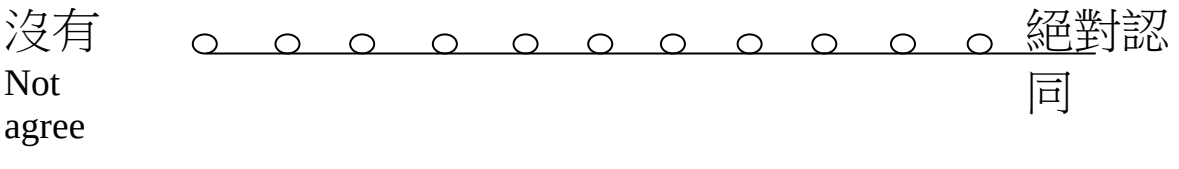
31.吞嚥問題影響了我跟陌生人一起吃飯。
Swallowing problems affect dinning together with strangers.



32.吞嚥問題影響了我的工作。
Swallowing problems affect my work.



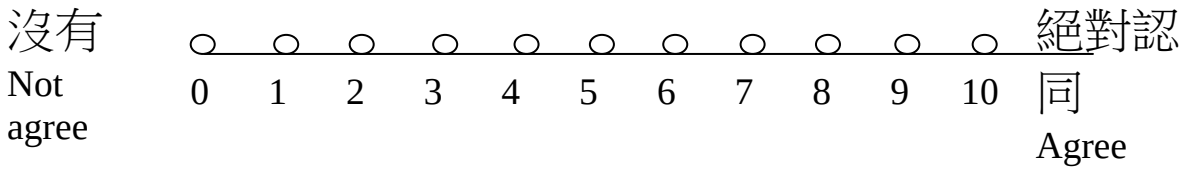
33.在過去一個月，我因為吞嚥困難而減少了工作。
In the last month, I reduced the amount of work due to my swallowing problems.



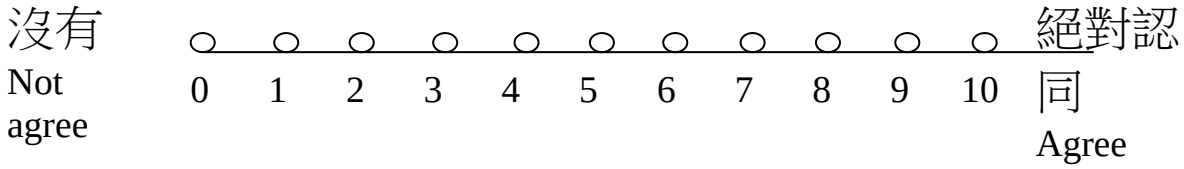
Agree

五.情緒上的影響

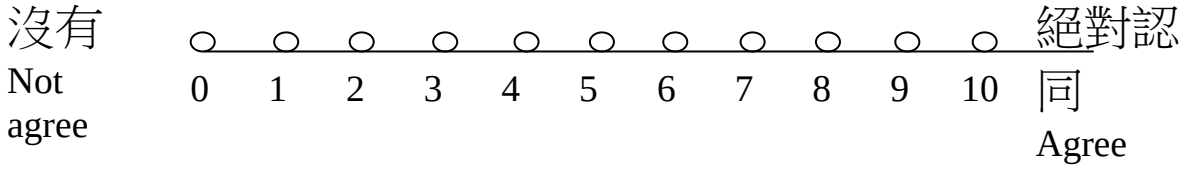
34.吞嚥問題令我感到不快樂。
Swallowing problems make me unhappy



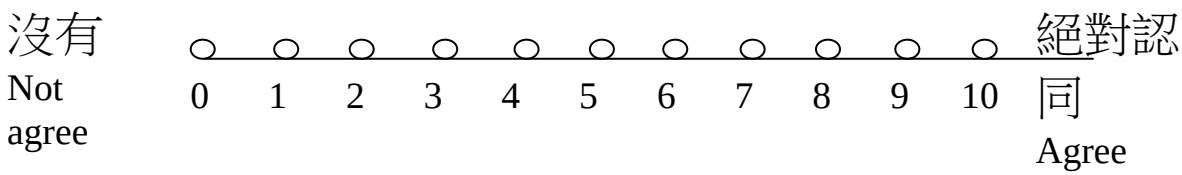
35.吞嚥問題使我感到尷尬。
Swallowing problems make me embarrassed.



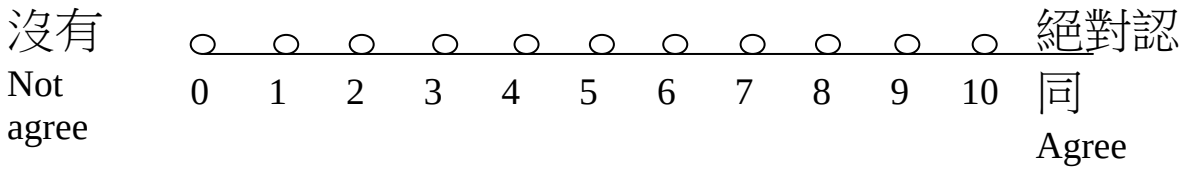
36.吞嚥問題令我的自尊心降低。
Swallowing problems lower my self-esteem.



37.吞嚥問題令我感到焦慮。
Swallowing problems make me anxious.



38.吞嚥問題使我感到煩擾。
Swallowing problems annoy me.



-問卷完-
-The end-