Artikel Asli/Original Article

The Swallowing Ability and Psychosocial Domains of Patients with Dysphagia Among Head and Neck Cancer Population

(Keupayaan Menelan dan Domain Psikososial Pesakit dengan Disfagia dalam Kalangan Populasi Kanser Leher dan Kepala)

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ABSTRACT

Dysphagia is a significant health issue and it gives a substantial impact on the individual's quality of life. This study aims to explore the quality of life of patients with dysphagia in head and neck cancer population. Twenty patients with dysphagia who were attending to oncology clinic in Hospital Universiti Sains Malaysia for their medical treatment on the head and neck cancer involved in the study. The Swallowing Activity and Participation Profile (SAPP) was used to gather information on the patients' swallowing ability and psychosocial domains (personal, social and working, and emotional). The results indicated that the swallowing ability was significantly related to the personal, social and working, and emotional domains. The Mann-Whitney test showed no statistically significant difference in the personal domain and in the social and working domain of men and women. Yet the result revealed a statistically significant difference in the emotional domain of men (M = 10.42) and women (M = 14.63). On the whole, this study positively conform that the quality of life of patients with dysphagia among head and neck cancer population was truly affected.

Keywords: Dysphagia; quality of life; psychosocial domains; swallowing ability

ABSTRAK

Disfagia ialah masalah kesihatan yang nyata dan ia memberi impak besar terhadap kualiti kehidupan pesakit. Kajian ini bertujuan untuk meninjau kualiti kehidupan pesakit disfagia dalam kalangan pesakit kanser leher dan kepala. Dua puluh orang pesakit disfagia yang menghadiri klinik onkologi di Hospital Universiti Sains Malaysia untuk rawatan perubatan kanser leher dan kepala telah menyertai kajian ini. Profil Penglibatan dan Aktiviti Menelan (SAPP) telah digunakan untuk mengumpul maklumat keupayaan menelan dan domain psikososial (peribadi, sosial dan pekerjaan, dan emosi) pesakit. Keputusan kajian menunjukkan bahawa keupayaan menelan berhubung secara signifikan dengan domain peribadi, domain sosial dan pekerjaan, dan domain emosi. Ujian Mann-Whitney menunjukkan tiada perbezaan statistik yang signifikan dalam domain peribadi dan dalam domain sosial dan pekerjaan terhadap lelaki dan wanita. Tetapi keputusan menunjukkan perbezaan statistik yang signifikan dalam domain emosi terhadap lelaki (M=10.42) dan wanita (M=14.63). Secara keseluruhan, kajian ini secara positif bersetuju bahawa kualiti kehidupan pesakit yang mengalami disfagia dalam kalangan pesakit kanser leher dan kepala sebenarnya terjejas.

Kata kunci: Disfagia; kualiti kehidupan; domain psikososial; keupayaan menelan

INTRODUCTION

Swallowing of food, liquids and saliva is a complex biomechanical interaction of physiology and anatomy that occurs in stages as pre-oral stage, oral stage, pharyngeal stage and lastly esophageal stage (Logemann 1997; Garden et al. 2006). There are six cranial nerves and 26 muscles involved in the swallowing process. Any neurological or structural defect that disrupts the swallowing process may result in dysphagia which is a swallowing dysfunction. Dysphagia is a disabling disorder from the functional point of swallowing. It is a symptom to indicate the disruption and/or impairment in the swallowing process of solids or liquids, starting from the oral cavity to

the stomach (Manikantan et al. 2009). Example of symptoms for swallowing problems include history of swallowing complaints, incidents of coughing, choking or regurgitation, difficulty or avoidance of some food consistencies, malnutrition, presence of feeding tube, any prior oral or oropharyngeal resection or chemoradiation, history of pneumonia or respiratory disease and presence of any previous neurological problems (Chen et al. 2001). Maltreatment of dysphagia could lead to malnutrition, dehydration, aspiration pneumonia, and even death (Sura et al. 2012; Singh & Hamdy 2006).

The social-emotional-relational implications are also a major factor which would hamper the quality of life (QoL) of a dysphagic individual (Verdonschot et al. 2013). Here,

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a collaborative swallowing rehabilitation management inclusive involvement of speech-language therapists is vital in improving a dysphagic individual's QoL and heighten the survival rate too. The QoL measures evaluate broad domains including emotional, physical, functional, social, financial, and spiritual well-being, and it has to be assessed from the patient's perspective instead of the clinician's perspective (Sayed et al. 2009).

Through the lens of WHO's International Classification of Functioning, Disability, and Health (ICF), apart from physiological alterations, dysphagia bring a remarkable deterioration in the daily activities and social function of the individual (Maclean et al. 2009). Owing to the fact that food plays an important sociocultural role in the society, swallowing difficulties can bring about mealtime anxiety and social withdrawal (Chen et al. 2009). Patients suffering from dysphagia have the risk of becoming isolated and depressed, since they find it difficult to participate in social activities (Nguyen et al. 2007). For example, having dinner in a social setting can cause fear of embarrassment subsequent to the inability to have normal swallowing function. The degree of depression, anxiety, and compromised quality of life that head and neck cancer patients experienced after treatment can be correlated with the severity of their dysphagia (Nguyen et al. 2005). Clearly, swallowing problems brings about physiological limitations as well as psychological alterations in a dysphagic individual. Dysphagia could condemn the pleasure of eating, especially when diet modifications are necessary to be implemented in a daily life of a dysphagic individual. Anxiety, associated with dysphagia, typically occurs when eating, and often when individuals want to eat by themselves. Study done by Ekberg et al. (2002) disclosed that many patients with dysphagia experienced panic or anxiety during mealtimes and avoiding eating with others. Briefly, the swallowing difficulties brought upon drastic changes in the patient's lifestyle, mainly their physical changes, mealtime experience and emotional experience. This conveyed the negative emotions felt by patients with dysphagia.

Head and neck cancer (HNC) is the most common malignant neoplasm arising in the mucosa of the upper aerodigestive tract (Grandis et al. 2004) including the paranasal sinuses, nasal cavity, oral cavity, pharynx, and larynx (Cognetti et al. 2008). Cancers in these areas would affect some of the most fundamental life functions including airway, digestion and speech (List et al. 1990; Nguyen et al. 2005). Furthermore, the mutilation and functional disability that sometimes results from the cancer and its treatment often changes an individual's perception of self and their interactions with others (List et al. 1990). The functional, psychological and social consequences of HNC and its treatment can be severe and chronic to the affected individual (Wells et al. 2016) and adversely affect a patient's QOL ability to eat (Chen et al. 2001).

Penner (2009) reported the psychosocial challenges experienced by head and neck cancer (HNC) individuals and

their family members. In the review, several implications had been mentioned which were (1) changes in appearance, (2) verbal communications, (3) eating and drinking challenges, (4) employment challenges, (5) challenges with sexuality, and (6) psychological distress within the patient and among the family members. Notably, more than half of the individuals who diagnosed with HNC experienced dysphagia. The review of the study also disclosed that the swallowing difficulties altered the patient's attribution to food and they were commonly disturbed with emotional fluctuation. It is common to have HNC patients present with the signs and symptoms of swallowing problems due to the primary neoplasm affecting the organ of swallowing and/ or because the treatment itself affects swallowing (Chen et al. 2001). Apart from that, those with moderate-to-severe dysphagia had significantly lower QoL compared to those with mild dysphagia. Despite this, social support appeared to be a key factor in alleviating the emotional distress and social dysfunction among the HNC patients with dysphagia. This particular review also pointed out the fact of limited investigations in examining the psychosocial intervention in relation to swallowing challenges among HNC patients. Undeniably, an abundant further investigation is summoned to explicate the psychological needs of both patients and their family members cross-sectional over time.

Choosing an appropriate inventory to investigate QoL of patient with dysphagia is important. The M.D. Anderson Dysphagia Inventory (Chen et al. 2001) and the Swallow Quality-of-Life Questionnaire (McHorney et al. 2000) were universally used questionnaire in discovering the QoL of individuals with dysphagia. However, the QoL of individuals with dysphagia is not deeply investigated in the emotional, functional and physical domains in MDADI. Meanwhile, the Swallow Quality-of-Life Questionnaire (SWAL-QOL) comes with complicated instructions and the scaling methods are not consistent through the whole questionnaire. Thus, Chan et al. (2012) developed Swallowing Activity and Participation Profile (SAPP) which considered the swallowing ability as well as the three psychosocial domains (personal, social and working, and emotional), which would adversely affect an individual with dysphagia.

The personal domain of the SAPP measured the extent of limitation or restriction that the individuals with dysphagia encountered in the personal daily life. The social and working domain of the SAPP measured the extent of limitation or restriction that the individuals with dysphagia experienced in the social and working area. The emotional domain of the SAPP measured the degree of emotional problem encountered by the individuals with dysphagia. In general, the extents of limitation of daily activities in different situations and restriction of participation in the corresponding psychosocial domains were the primary concern in this SAPP. The significant high correlation test (Pearson's r = -0.89, p < 0.0001) was found between SAPP and MDADI indicated that SAPP is qualified and reliable to be used to discover the QoL of individuals with dysphagia.

Some studies have shown dissimilarities finding of gender aspect on psychosocial and emotional effect among patients with dysphagia. Lotter (2015) conducted a pseudoqualitative study to discover the psychosocial effects of dysphagia among adults with a non-terminal, nonprogressive neurological condition. The results presented that the common psychosocial effects experienced by patients with dysphagia were frustration, embarrassment, depression, and contentment due to the inability to enjoy mealtime. The results also showed significant gender differences on psychosocial effects of dysphagia. Women were more emotionally distressed compared to men. Lotter (2015) urge the SLTs to be aware of the adverse effects of dysphagia to ensure more efficient methods in improving or regaining the swallowing skills and at the same time enhancing the QoL among patients. Eslick and Talley (2008), however, showed that there was no significant association regarding psychosocial effect of dysphagia in comparison of gender. Nonetheless, Lango et al. (2014) study on the baseline dysphagia associated with emotional effect discovered gender differences among head and neck cancer population.

As patients with dysphagia facing variety of challenges, the purpose of this study is to identify the quality of life among these patients. Specifically, this study aims to examine the relationship between swallowing ability and the three psychosocial domains (personal, social and working, and emotional domains) and to examine gender differences within these domains. The findings could aid in speech language therapist and professional multi-teamwork planning of intervention program in the role of providing optimal management care to patients with dysphagia.

It is prominent that an individual's functioning and QoL are an important health matter to consider, together with survival, for patients with dysphagia among HNC population (Murphy et al. 2007). Nonetheless, there has not been any publication or report on the QoL of patients with dysphagia among HNC population in Hospital Universiti Sains Malaysia (HUSM) as this is a teaching and referral hospital located in Kubang Kerian, Kelantan. As a preliminary study, this paper aimed to assemble information regarding the QoL of patients with dysphagia in HNC population.

EXPERIMENTAL METHODS

STUDY DESIGN AND PARTICIPANTS

A cross-sectional study was carried out on HNC patients with dysphagia in Oncology Clinic, HUSM. All the patients were undergoing chemoradiation therapy (CRT). The data collection was conducted in two months' time, from March 2016 to April 2016. A shortlisted daily attendance of HNC patients with dysphagia was obtained, and then a short interview with the patients was conducted to reaffirm the inclusion and exclusion criteria.

The participants were the patients with the onset of dysphagia due to medical treatment, alert and conscious state, intact language comprehension, and with regular experience of one or more of the subjective dysphagiarelated symptoms such as; difficulty in swallowing or no oral intake, frequent coughing and excessive coughing during mealtime, individual mealtime with supervision, history of aspiration pneumonia, diet modification, and non-oral nutritional support. Patients with impaired level of consciousness, unable to express using any means of communication, weak physical condition, experienced Traumatic Brain Injury (TBI) or Motor-Vehicle Accident (MVA), and with regular experience of loss of appetite or mild throat discomfort only were excluded from the study. The study objective was explained to obtain the participation consent before the distribution of the questionnaire. Upon distribution, the researchers were presented nearby the participant to aid the participant to understand the written survey better if necessary. The time for completion of the questionnaire was about 30 minutes, and the participants were granted with honorarium. Ethical approval for this study was obtained from Research and Ethics Committee (Human), Universiti Sains Malaysia.

MATERIALS

The Swallowing Activity and Participation Profile (SAPP) questionnaire (Chan et al. 2012) was used as it was culturally and socially compatible. The SAPP consisted of four main variables (the swallowing ability and the three psychosocial domains [personal domain, social and working domain, emotional domain]). The score of these four variables were computed together to obtain the total score of SAPP, reflecting the QoL among the patients with dysphagia.

In this study, the questionnaire consisted five parts, inclusive basic personal details, the swallowing ability, and the three psychosocial domains (personal domain, social and working domain, and emotional domain). This self-administered questionnaire comprises of 38 questions was translated into Malay language. The face and content validity of Malay-translated version questionnaire was made to ensure the accuracy of the items. Six panels (three Chinese medical officers and three Malay medical officers in respective fields) were involved in the content validation of Malay-translated version questionnaire, while the face validation included two randomly chosen patients with dysphagia and three final year speech-language pathology students. The process led to minor changes in wording and formatting of the items in the questionnaire considering the cultural and social compatibility. In the current study (total of 20 participants), the Cronbach alpha coefficient was .84 for the swallowing ability, .84 for personal domain, .82 for social and working domain, and .82 for emotional domain. Overall, these scales have good internal consistency.

The swallowing ability questionnaire aims to identify the extents of the swallowing ability among patients with dysphagia including situations during and after the intake of solid and liquid. This part of questionnaire consists of 10 items and is rated using a six-point Likert scale (never to always). The part of personal domain aims to identify the extents of the swallowing ability in different situations in personal life. It consists of 10 items. For each situation in this part, a pair of statements was asked in which the first statement of each pair concerned the extent of limitation in daily personal activities as a result of the swallowing ability. The second statement of the pair concerned the extent of restriction in participating personal activities. Next, the part of social and working domain aims to identify the extents of the swallowing ability in different situations in social and working life. This part consists of nine items. Finally, the part of emotional domain aims to identify the extents of the swallowing ability in different aspects of the emotion in the individual. This part consists of five items. All items in personal domain, social and working domain, and emotional domain are rated using a four-point Likert scale (strongly disagree to strongly agree).

The Spearman's Rank Correlation Coefficient was used to determine the correlation between the swallowing ability and each of the psychosocial domains (personal domain, social and working domain, and emotional domain). The Mann-Whitney test was used to test for differences between gender in terms of personal domain, social and working domain, and emotional domain.

RESULTS

DEMOGRAPHIC PROFILE OF RESPONDENTS

Table 1 shows the demographic profile of the subjects. There were 20 participants (12 men and 8 women). Among them, a total of 25% of participants were within the age span of 40 to 49 years old, 35% participants aged in the range of 50 to 59 years old, and 40% participants aged within the age span of 60 to 69 years old. With corresponds to races, 19 patients were Malay and only one was Chinese, the same figures refer to religion. Regarding occupation, four (20%) participants were involved in business and two patients were non-professional workers (farmer and police staff). Meanwhile, a total of 45% participants were unemployed and 25% participants were retired. Concerning marital status, a majority (85%) of them was married, and two (10%) participants were single. Only one participant was a divorcee.

DIET INFORMATION

None of the 20 patients reported with the experience of aspiration pneumonia. Table 2 shows type of food consumed by the patients. With reference to the rice diet partakes, nine (45%) patients partake of rice paste (including porridge), six (30%) patients consumed soft rice, two (10%) patients consumed rice with soup, and three (15%) patients could not tolerate any type of rice modification at all. As to type of meat preparation, 14 (70%) patients totally did not consume any type of meat modification. Only two (10%) patients were orally tolerated with the normal texture of

TABLE 1. Demographics profiles of the patients

Demographics	Men	Women	Total	
	n (%)	n (%)	n (%)	
Age				
40 - 49	4 (20)	1 (5)	5 (25)	
50 - 59	3 (15)	4(20)	7 (35)	
60 - 69	5 (25)	3 (15)	8 (40)	
Races				
Malay	11 (55)	8 (40)	19 (95)	
Chinese	1 (5)	-	1 (5)	
Religion				
Islam	11 (55)	8 (40)	19 (95)	
Buddha	1 (5)	-	1 (5)	
Occupation				
Non-professionals	2 (10)	-	2 (10)	
Business	3 (15)	1 (5)	4 (20)	
Unemployed	4 (20)	5 (25)	9 (45)	
Retired	3 (15)	2 (10)	5 (25)	
Marital status				
Single	2 (10)	-	2 (10)	
Married	10 (50)	7 (35)	17 (85)	
Divorced	-	1 (5)	1 (5)	

meat and one (5%) patient consumed minced meat. In terms of blended paste of meat, two (10%) patients partake of it. Only one (5%) patient reported consuming small and thinly sliced meat. Concerning the type of vegetable preparation, seven (35%) patients totally did not consume any type of vegetable diet. Six (30%) patients were orally tolerated with the normal texture of vegetables and three (15%) patients partaken minced vegetables. Four (20%) patients partake of blended paste of vegetables. In terms of beverage, all patients were consuming drinks (water and milk) as normal without the addition of thickener to modify the consistency for the ease of swallowing.

TABLE 2. Type of food consume by orally-intake patients

Type of food	Number of patients (%)		
Rice modification			
Rice with soup	2 (10)		
Soft rice	6 (30)		
Rice paste	9 (45)		
No rice at all	3 (15)		
Meat modification			
Normal texture of meat	2 (10)		
Small-thinly sliced meat	1 (5)		
Minced meat	1 (5)		
Blended paste of meat	2 (10)		
No meat at all	14 (70)		
Vegetables modification			
Normal texture of vegetables	6 (30)		
Minced vegetables	3 (15)		
Blended paste of vegetables	4 (20)		
No vegetables at all	7 (35)		

ANALYSIS OF THE SWALLOWING ACTIVITY AND PARTICIPATION PROFILE (SAPP)

The swallowing abilities of the participants and the effects of it on the psychosocial domains as scored in SAPP were analyzed and tabulated in Table 3. The mean score for swallowing ability was 16.00 (SD 10.57). The average total score of SAPP indicates the effect of dysphagia on patients' psychosocial states was moderately severe. A severity scale with three subscales (mild, moderate, and severe) was presented to provide a clear indication of the extent of restriction in the three psychosocial domains (Table 4). Among the 20 patients, 11 of them disclosed fairly severe on personal domain, while about seven to nine patient have mild to moderate score for social and working domain and also emotional domain.

TABLE 3. The descriptive data of the SAPP scored by patients

	Mean	SD	Min	Max
Total Score of SAPP				
(Max: 146; Min: 24)	77.35	22.22	37.00	115.00
Swallowing Ability Score				
(Max: 50; Min: 0)	16.00	10.57	3.00	39.00
Personal Domain Score				
(Max: 40; Min: 10)	30.30	6.17	14.00	39.00
Social and Working				
Domain Score				
(Max: 36; Min: 9)	18.95	6.41	9.00	29.00
Emotional Domain Score				
(Max: 20; Min: 5)	12.10	4.01	5.00	20.00

TABLE 4. The distribution of the severity level in the psychosocial domains

Psychosocial domains	Scoring	Severity subscales	Number of patients (%)
Personal	10 – 20	Mild	2 (10)
	21 - 30	Moderate	7 (35)
	31 - 40	Severe	11 (55)
Social and	9 - 17	Mild	7 (35)
working	18 - 26	Moderate	8 (40)
	27 - 36	Severe	5 (25)
Emotional	5 - 10	Mild	7 (35)
	11 - 15	Moderate	9 (45)
	16 - 20	Severe	4 (20)

ANALYSIS OF THE RELATIONSHIP BETWEEN THE SWALLOWING ABILITY AND THE PSYCHOSOCIAL DOMAINS

Table 5 shows the correlation between swallowing ability and psychological domains. The Spearman's Rank Correlation Coefficient showed a significant correlation between the swallowing ability and each of the psychosocial domains [swallowing ability and the personal domain (r = .59); swallowing ability and the social and working

domain (r = .70); swallowing ability and the emotional domain (r = .48)]. The correlation was significant at the 0.05 level (2-tailed). The Mann-Whitney test revealed there is no significant difference between gender in the personal domain (z statistic = .54, p value = .59) and in the social and working domain (z statistic = .27, p value = .79). However, in the emotional domain the z value is 2.10 with a significance level of p = .04. The probability value (p) is less than .05, so the result is significant. There is statistically significant difference in the emotional domains scores of women and men. The results showed the women having significantly higher value of mean and median on the emotional domain compared to the men.

ANALYSIS OF THE PSYCHOSOCIAL DOMAINS BASED ON GENDER

Further analysis was carried out to examine the difference between gender upon the three psychosocial domains. Data in Table 6 disclose the scores of mean, median and standard deviation in the three different psychosocial domains with reference to gender.

TABLE 5. Spearman's Rank Correlation Coefficient between the swallowing ability and psychosocial domain

Psychosocial domains	Swallowing ability		
Personal	.59**		
Social and working	.70**		
Emotional	.48*		

TABLE 6. Mean, median and standard deviation of psychosocial domains based on gender

Psychosocial		Women		Men		
domains	Mean	Median	SD	Mean	Median	SD
Personal	30.75	31.50	6.90	30.00	30.50	5.92
Social and working	19.75	18.50	5.70	18.42	19.00	7.05
Emotional	14.63	13.00	3.89	10.42	11.00	3.23

DISCUSSION

The changes of swallowing abilities are adversely affecting the individuals (Francis et al. 2010; Nguyen et al. 2002). In the present study, majority of the patients were experiencing different degree of impacts due to dysphagia in their daily living. This different degree of impacts would ultimately lead to the risk of malnutrition and dehydration which would put them into threatens of life. In order to cope with the negative situations, dietary modification is the best option for the patients to meet their daily nutritional requirements for the sake of survival (Garcia & Chambers 2010; Garcia, Chambers & Molander

2005). In this study, patients were practicing tailored dietary modification in order for them to get an adequate nutrition for daily functioning. Many of the patients took soft structured of rice and vegetables, and majority of them do not take meat at all.

The average total score of SAPP indicates the effect of dysphagia on patients' psychosocial states was moderately severe. The potential of an individual to perform appropriately in areas of eating and speaking significantly effects a wide range of psychological well-being from social and family interactions to more internalized feelings of self-esteem and competence (List et al. 1990). According to Ekberg et al. (2002), patients experienced psychological problems as anxiety or panic during mealtimes and even avoided eating with their social circle because of their psychological states due to dysphagia. Moreover, Roche (2003) and Finucane, Christmas and Travis (1999) stated that existence of alternate feeding methods could promote a cascade of negative psychosocial features as depression and loss of social interaction associated with feeding.

The personal domain of the SAPP measured the limitation level that the patients with dysphagia experienced in their daily life. The results disclosed that only a minority of patients reported to have mild-to-moderate limitations of their personal daily functioning, while the majority of them showed up severe limitations, as a result of the dysphagia. This reflected that dysphagia significantly diminished the individuals' eating pleasure as their mealtime was affected quantitatively and qualitatively (Nund et al. 2014; Ottosson et al. 2013). Due to the restriction in the swallowing ability, the patients had to spend more time to chew the food carefully (Raber-Durlache et al. 2012) and considering the incidence of coughing or choking during the swallow (Denaro et al. 2013). Patients with dysphagia also have to deal with interval breaks between mealtimes as the swallowing difficulties could lead to fatigue. Moreover, dietary modification altered the texture and taste of food which might lead to the lack of appetite and anticipation towards mealtime (Keller et al. 2012). In short, patients with dysphagia undergone reduce of food intake, extended mealtime, and restriction in intake of favorite food or drinks. This indirectly forces them to alter their perceptions towards food and change in appreciation of food, which in turn affecting their social functioning with undergoing emotional changes while dealing with the altered perception (Raber-Durlache et al. 2012).

The social and working domain of the SAPP measured the restriction that the patients with dysphagia encountered in their social and working domain. The majority of the patients reported to have mild-to-moderate restriction in their social and working domain, while some of them stated severe limitations. Because problems with swallowing required an extended time to finish eating, it causes the patient to avoid eating around others, share in meals at significant events or celebrations, or eating in the public (List et al. 1990). Moreover, the limitations in food choices and textures made it more challenging when eating outside

as much as unpredictable risk that they would not be able to eat the served food and the café or restaurants would not be able to accustom to their dietary modification. The swallowing problems also restricted them to be actively involved in their daily house chores especially after the chemoradiation therapy. Difficulty swallowing and strict dietary limitations can cause negative effects on patient health, making them feel unwell and fatigued, as well feeling of weakness or weariness (National Cancer Institute 2014). However, this is not necessarily applicable on all the HNC patients as it also depends on how severe the side effects are. Some patients are able to go to work, do house chores, and enjoy leisure activities while they are receiving the radiation therapy while others find that they need more rest than usual and, therefore, unable to participate in daily activities much (National Cancer Institute 2014).

The emotional domain of the SAPP measured the extent of emotional problem encountered by the patients with dysphagia. The majority of the patients reported to have moderate-to-severe emotionally burdened with dysphagia, while only a few participants were experienced mild emotional hardship. Inability to have a socially-acceptable table eating manners could bring upon the feeling of frustration to the patient himself or herself and also feeling of shame and embarrassment within the family and friends. The disturbed self-perception unconsciously might lead to the patient's decision to be secluded from the social circle. Eating, in fact, have a significant impact on the patient's emotion because it could represent as a social behavior act whereby one eats to interact and socialize within the social circle to receive comfort apart from sustaining optimal nutritional status for survival. Thus, loss of this type of social contact could lead to social isolation and risk of depression. Nonetheless, the findings disclosed that the family members showed some tolerant towards the patient's condition. It is an essential survival point for patients with dysphagia.

The findings also revealed an emotional difference between gender where men seem to experience less emotional difficulty compared to women. Probably, men were more opened to their physical changes and the detrimental changes in their lifestyle compared to women. On the other hand, men and women have different intrinsic regulation system which brings different emotional experiences. Women tend to absorb and retain more sensorial and emotive information than men do (McRae et al. 2008). In this study, the majority of women reported feeling miserable due to their inability to enjoy their mealtime, whereas, the majority of the men appeared to be taking it as easy as possible. The finding correlate with Lotter (2015) study where men and women with dysphagia significantly difference in emotional experience, markedly women appeared to be more affected. Thus, the difference between men and women in attributing and regulating their emotions are an important factor to be considered during rehabilitation management to ensure optimal outcomes, which improves the QoL as well. Supportive therapies inclusive of more praise, empathy, affiliation and emphasis on strengths and talents, help women to achieve a better outcome (McRae et al. 2008). On the other hand, the results indicated there was no significant difference between gender in the perception towards their personal as well as social and working domains, which concur with other studies (e.g. Sabaretnam et al. 2012; Lango et al. 2014). This suggestive the perception towards the personal as well as social and working domain was mainly influenced by external factors (e.g. physical changes, support system), but the perception towards emotional domain was more intrinsically influenced (Lango et al. 2014).

Terrell et al. (2004) emphasized that when there is a present of two different treatment modalities with similar survival rates, the QoL factors are the crucial consideration for patients. As follows, the present study has utilized the SAPP which enables the clinicians to look into the effects of swallowing disorder in different domains easily such as the social, personal, and emotional domains to identify the QoL. By monitoring the QoL of patients with dysphagia, researcher will be able to identify the swallowing related QoL which will be helpful for the clinicians to have a clear picture on the patient's swallowing ability and design more suitable and convenient treatment approach for the patient (Maclean et al. 2009). Knowing the swallowing related QoL may also help in prioritizing the treatment goals for the HNC patients as the treatment can be individualized to the area that affected the particular patient most. Moreover, identifying the QoL of patient with dysphagia helps the clinicians to view the swallowing disorder from broader viewpoints.

CONCLUSION

Dysphagia brings a substantial impact on patient's life. Patients suffering from dysphagia have the risk of becoming isolated and depressed as they find it difficult to engage in social activities. Generous emotional and physical supports from the social circle are very important for them as the social closeness could set off positive emotional experience to the patients. of patients with dysphagia among head and neck cancer population The management of patients by a multidisciplinary team, which includes a speech and language therapist, is necessary to successful outcomes for the head and neck cancer patient with dysphagia. A dedicated multidisciplinary team in dysphagia management have to be sensitive to the patient psychosocial issues for the sake of maximizing the safety of oral intake while caring for the patient life quality. Even though there are many previous studies found that dysphagia is correlated with poor QoL, there has not been any publication or report on the Malaysian population who has different culture and the outcome of the correlation of dysphagia with QoL would also be different. Thus, this study has identified the QoL of patients with dysphagia among HNC population in Hospital Universiti Sains Malaysia (HUSM) to further reassure the result within our culture. Moreover, the contribution of this study in measuring and identifying QoL of patient with dysphagia offer a means for demonstrating treatment

impact and for improving medical care. A limitation of this study was the small sample size where it might restrict the analysis of the psychosocial differences between gender. A larger sample size could address the QoL of patients with dysphagia more comprehensively.

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