



## Assessment of quality of life in individuals with dysphagia: a questionnaire in Marathi

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### Key Words

*Dysphagia  
Questionnaire  
Quality of life  
Impact of dysphagia*

### Abstract

*The study aimed at developing a questionnaire for assessing quality of life in individuals with dysphagia. The study was carried out in two phases; first phase included preparation of a questionnaire in English which was later translated to Marathi using forward and backward translation. In the second phase, the developed questionnaire was administered on thirty-five adults with dysphagia. Item analysis was performed on scores obtained for each statement of the questionnaire by individuals with dysphagia. Eight items required deletion after inter-item correlation leaving 47 statements in the final questionnaire, Dysphagia Quality of Life Questionnaire in Marathi (D-QOL-QM), which were divided into four sections; functional, eating, psychosocial and, physical section. Overall cronbach's alpha coefficient was very high ( $\alpha=0.93$ ) which shows that the questionnaire has good reliability. Results on Pearson's correlation showed good internal consistency and highly significant moderate to high correlation for sections of questionnaire. This study provides a reliable clinical tool, D-QOL-QM, for assessing impact of dysphagia on individual's life in Indian scenario.*

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### Introduction

The World Health Organization (WHO) defines health as "A state of complete physical, mental, and social well-being not merely the absence of disease." It follows that the measurement of health and the effects of health care must include not only an indication of changes in the frequency and severity of diseases but also an estimation of well being and this can be assessed by measuring the improvement in the quality of life related to health care. Quality of life can be viewed in four dimensions viz. mental health, physical functioning, social functioning and role functioning (McHorney, 2000). According to WHO, the quality of life in an individual may be affected by impaired physical health, psychological state, level of independence, social relationships, personal beliefs and environment related factors. Dysphagia affects the most fundamental of human functions, the ability to eat and drink and is associated with wide range of speech and language disorders. It has a negative effect on all aspects of a person's life, including work, leisure, and social situations. Dysphagia has been associated with wide range of speech and language disorders and studies have reported that it has a significant effect on an individual's quality of life with several diseases and conditions. Researchers have reported a significant

reduction in their quality of life for individuals with Parkinson's disease -PD (Leow, Huckabee & Beckert, 2010), stroke (Kwok, Wong, Mok & Kai, 2006), and Huntington's disease. Studies done to see the impact of dysphagia on patients with head and neck cancers indicates that quality of life is affected in these individuals but its effect varies with type of treatment like radiotherapy, surgery or chemotherapy (Gillespie, Brodsky, Day, Lee & Martin-Harris, 2004). Studies have reported that quality of life is increasingly compromised with increase in dysphagia severity (Dwivedi et al., 2010), and some patients preferred to have less life span rather than compromised quality of life (Deleyiannis, 1997). Individuals with head and neck cancer reported that dysphagia maximally impairs their psychosocial aspects of their life (Ekberg, Hamby, Woisard, Hannig & Ortega, 2002; Maclean, Cotton & Perry, 2009). These studies have concluded that individuals who experienced dysphagia had greatly reduced quality of life.

There are satisfactory ways of measuring the frequency and severity of diseases. However, there are limited ways of measuring individuals' well-being and quality of life. Thus it is important to have measures which assess quality of life in order to obtain individual's self-perception. There are generic, disease-specific, swallowing phase spe-

cific scales, questionnaire, and inventories to assess quality of life in individuals with dysphagia. Some of widely used generic tools are the swallowing quality of life outcomes tools-SWAL-QOL (McHorney et al., 2000), the Dysphagia Handicap Index -DHI (Silbergleit, Jacobson & Johnson, 2012), Deglutition Handicap Index (Woisard & Lepage, 2010). Disease specific tools to assess quality of life are Dysphagia Goal Handicap-DGH (Gustafsson & Tibbling, 1991), Parkinson's Disease Questionnaire - PDQ-39 (Peto & Jenkinson, 1998), the MD Anderson Dysphagia Inventory-MDADI (Chen et al., 2001), the scale of the Quality of Life in Parkinson's Disease-Parkinson's disease Quality of Life scale - PDQUALIF (Welsh, McDermott & Holloway, 2003), The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - H&N35-EORTC-QLQC35 (Chaukar et al., 2005), performance status scale for head and neck cancer patients-PSS-HN (Marcy, Ritter, Shirley & Lansky, 2006) Swallowing Disturbance Questionnaire-SDQ (Manor, Fliss & Cohen, 2007), and the Mayo Dysphagia Questionnaire-30 -MDQ -30 (McElhiney et al., 2009). These questionnaires have been used widely by studies to analyse quality of life in individuals with dysphagia following Parkinson's disease, Huntington's disease, stroke, and cancers of head and neck using various inventories and developed questionnaires. Moreover some of these researchers have reported a significant reduction in quality of life for individuals with Parkinson's disease (Plowman-Prine et al., 2009; Leow, Huckabee & Beckert, 2010), stroke (Kwok, Pan, Lo & Song, 2011) using SWAL-QOL and for Huntington's disease using SDQ.

Researchers are using subjective clinical examinations and objective tools to evaluate swallowing. Advances have been made in measuring the physiologic outcomes of dysphagia, including measurement of duration of structure and bolus movements, stasis, and penetration aspiration. There is noticeable change in researcher's attitude with inclination towards quality of life research. In western literature, researchers have developed various questionnaires, inventories, scales and outcomes tools for assessing quality of life in individuals with dysphagia. However to best of researchers' knowledge there is no tool available for assessing quality of life of individuals with dysphagia in Indian scenario. Therefore, this study aimed at devising a questionnaire for assessing quality of life in individuals with dysphagia.

## Method

The study was carried out in two phases; first phase included preparation of a questionnaire to assess quality of life in individuals with dysphagia, and second phase was administration of the

developed questionnaire on individuals with dysphagia.

**Preparation of Questionnaire:** While preparing the statements for the questionnaire focus was given on difficulties faced by individuals with dysphagia and its effects on their quality of life. The patient's perspectives on components of everyday life that are impacted due to dysphagia were taken and statements were formed based on quality-of outcomes from individuals with dysphagia and their caregivers. Five individuals with dysphagia and their caregivers' opinions were considered while selecting the questionnaire. While preparing statements for questionnaire, WHO-QOL was referred and ICF domains for swallowing disorders were taken into account. Also a careful review of generic and specific questionnaires available in literature of dysphagia was done.

**Construction of Statements and Rating Scale:** Sixty statements along with rating scale initially were made in English. Statements were made with simple, universally understood words and in conversational language. It was made with one attribution per statement. Items were free of age, gender, and social class biases. A five point rating scale was prepared for noting responses of individuals with dysphagia. It was kept in mind that rating scale matched all statements in questionnaire.

**Translation Procedure:** Translation procedure as described by the international guidelines given by Guillemin, Bombardier and Beaton (1993) was adopted while preparation of the questionnaire. Statements along with rating scale initially were made in English and later forward translation was done into Marathi by bilingual translator whose mother tongue was Marathi. Then backward translation was carried out by a different bilingual professional translator whose mother tongue was Marathi but he was very proficient in English language. He translated the Marathi version of statements into English.

Three experienced speech language pathologists evaluated whether the constructed statements were pertaining to individuals with dysphagia. Modifications and changes were made in the questionnaire depending on feedback and opinions received from these expert Speech Pathologists. Some of the suggestions included; considering social situations in Maharashtra, rephrasing and few statements. Simple, straightforward statements pertaining to difficulties faced by individuals with dysphagia were kept whereas difficult, complex, ambiguous sentences were eliminated. Five statements were removed from initial questionnaire due

to less relevance of them towards QOL in dysphagia. Finally fifty five statements comprised in the questionnaire. Responses were taken on a five point rating scale (never-1, hardly ever-2, sometimes-3, often-4, almost always-5). A response column on questionnaire along with the case history was made which contained history regarding demographic data, medical diagnosis, information regarding other medical illness, medication with dosage dysphagia symptoms and occupation information. It also comprised of details such as questionnaire filled with help of family member or self.

### Administration of the Questionnaire

**Participants:** Thirty five individuals participated in the study within the age range of 29 to 85 years with mean age of 59.3 years having varying aetiology, type and severity of dysphagia. Participants were taken as per availability from various clinics, hospitals and special self- help groups in and around Pune city. Participants with persisting dysphagia for minimum of one month were included. All participants were diagnosed with oropharyngeal dysphagia of mechanical or neurogenic type by medical professional or SLP. Participants who were hospitalised, severely ill, or medically unstable were excluded. Participants with known history of language, cognitive, psychiatric, reading, writing and visual impairment were excluded. Participants were allowed to use spectacles, if required.

**Procedure:** Each participant was given a 'participant information sheet' which included description about the present study. They were informed that they are required to answer a set of questions related to their swallowing difficulty. They were explained that their information will be kept confidential, participation in the study is voluntary, and they can withdraw from the study if they wish. A written consent was taken from each participant before administration of the questionnaire. A detailed case history was taken for each participant who included demographic data (name, age, gender, occupation, address and phone number), detailed medical history, duration of dysphagia, tolerant consistency of food, dysphagia symptoms like pneumonia, weight loss and sudden fever. Information regarding individual who filled the questionnaire i.e., self, family, or others was also taken. Presence of dysphagia was reported by medical professional and was diagnosed by speech language pathologist using Manipal manual of swallowing assessment - MMSA (Kumar & Bhat, 2012).

The questionnaire developed in this study was administered on participants using interview method by authors of this study. If required, participants were allowed to take assistance from close family member or caretaker. Participants were instructed that all statements were related to their

eating and swallowing aspects and they were required to rate what they have been feeling regarding their swallowing for the last one month. The responses of the participant were taken for each statement using a five point rating scale i.e. 'never' scored as 1, 'hardly ever' as 2, 'sometimes' as 3, 'often' as 4 and 'almost always' as 5. While administering the questionnaire, if required, statements were re-read to the participants but not rephrased. The response for each statement was noted by the examiner on the response column provided in the questionnaire. Total score was calculated for each section of the questionnaire based on the responses given by individual with dysphagia. Higher scores indicated more impact of dysphagia on individual's quality of life.

**Statistical Analysis:** Descriptive statistics was obtained for total score and for each statement of the questionnaire. For reduction of statements, item analysis was done and to check reliability of the developed questionnaire, Cronbach's alpha coefficient was obtained. Pearson's correlation coefficient was calculated to check internal consistency of the questionnaire.

## Results

In the present study we have been able to present a questionnaire to document quality of life in individuals with dysphagia. Participants included individuals with neurogenic dysphagia as well as with mechanical dysphagia.

### Sections of D-QOL-QM

The Dysphagia Quality of Life Questionnaire in Marathi (D-QOL-QM) was developed in the present study which comprised of statements related to quality of life in individuals with dysphagia. Based on literature available on quality of life in dysphagia, ICF for dysphagia (Threats, 2007) and various quality of life scales in dysphagia, statements of the D-QOL-QM were divided into four sections; (a) Functional section included statements related to overall impact of dysphagia on activities of daily living (b) Eating section comprised of statements related to the impact of dysphagia on diet, eating duration, food type, consistency and quantity, food preferences, assistance in eating, and appetite (c) Psychosocial section included statements related to impact of dysphagia on emotional and social aspects where participation of individuals in his/her swallowing environment is focused (d) Physical section had statements pertaining to problems arising during the act of swallowing due to structural or neurological deviations.

### Administration Time and Method

Administration time of the questionnaire ranged between 15 and 20 minutes for most partici-

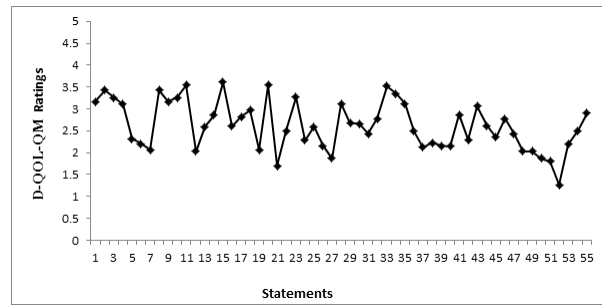


Figure 1: Shows means of ratings for individuals with dysphagia for each statement.

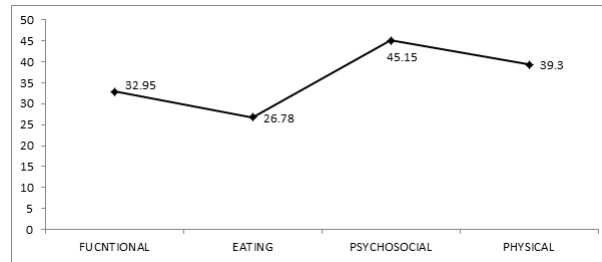


Figure 2: shows means of subsections of D-QOL-QM questionnaire

Table 1: Shows description of the statements which were showed low alpha value

Statement No.	Description	Inter-item correlation
F <sub>unc</sub> -S5	Due to my swallowing / eating problem usual leisure activities are limited.	r=0.112
E <sub>ating</sub> -S21	Due to my swallowing / eating problem I am not able to feed myself.	r=0.162
P <sub>ychSoc</sub> -S26	Due to my swallowing / eating problem my family and friends get irritated with me	r=0.183
P <sub>hysical</sub> -S41	I find it difficult to drink liquids because I choke while swallowing	r=0.202
P <sub>hysical</sub> -S42	I find it difficult to eat because I choke while eating	r=0.242
P <sub>hysical</sub> -S43	I find it difficult to eat because I gag while eating or drinking.	r=0.130
P <sub>hysical</sub> -S44	Because of difficulty in chewing I find it difficult to eat.	r=0.244
P <sub>hysical</sub> -S48	Because of food sticking in throat I find it difficult to swallow	r=0.229
P <sub>hysical</sub> -S49	Because of food coming out from nose I find it difficult to eat	r=0.15
P <sub>hysical</sub> -S50	I find it difficult to eat because, food spills from mouth.	r=0.242
P <sub>hysical</sub> -S52	I feel pain while drinking	r=0.023
P <sub>hysical</sub> -S55	I find it difficult to eat because I drool while eating	r=0.148

pants with exception of 30 minutes required by two participants. The dysphagia quality of life questionnaire was administered on each participant by investigator of the study using interview method. Most of the participants self-rated the questionnaires on their own except few (6 participants) who required caretaker’s help to respond.

**Item analysis**

Item analysis was performed on scores obtained on the 55 statements of the D-QOL-QM by individuals with dysphagia. For reduction of statements from the questionnaire inter-item analysis was done which tested significance of each statement with total score and certainty of statement to be retained, rejected or modified in D-QOL-QM. Inter-item consistency was checked where each item was correlated with the total score for reduction of items. Item was deleted if correlation coefficient was lesser than 0.3 or greater than 0.8 ( $0.8 > r < 0.3 =$  item deleted). Many ques-

tionnaires developed in western literature for assessing quality of life in dysphagia, consider lowest inter-item correlation value as 0.30 and highest as 0.80. Therefore same criterion was used in present study for inter-item correlation. Considering this criteria, 12 statements required deletions which are shown in Table 1. Statements number, F<sub>unc</sub>-S5 (r=0.112), E<sub>ating</sub>-S21 (r=0.162), P<sub>ychSoc</sub>-S26 (r=0.183), P<sub>hysical</sub>-S41 (r=0.020), P<sub>hysical</sub>-S42 (r=0.242), P<sub>hysical</sub>-S43 (r=0.130), P<sub>hysical</sub>-S44 (r=0.244), P<sub>hysical</sub>-S48 (r=0.229), P<sub>hysical</sub>-S49 (r=0.243), P<sub>hysical</sub>-S50 (r=0.242), P<sub>hysical</sub>-S52 (r=0.023), P<sub>hysical</sub>-S55 (r=0.148) showed poor correlation with total score and hence required deletion. However, 4 statements out of 12 were retained due to high theoretical basis and its relevance to quality of life of individuals with dysphagia. Statement number E<sub>ating</sub>-S21 (Due to my swallowing / eating problem I am not able to feed myself.), P<sub>hysical</sub>-S44 (Because of difficulty in chewing I find it difficult to eat), P<sub>hysical</sub>-S48 (Because of food sticking in throat

I find it difficult to swallow), and  $P_{physical}$ -S50 (I find it difficult to eat because, food spills from mouth) were retained in D-QOL-QM as they assessed important domains of dysphagia.

It was noted that the 8 statements which were deleted, did not change the overall cronbach's alpha value of the questionnaire (Table 2). The cronbach's alpha obtained in the study exceeds the minimum acceptable value suggesting that each statement of the questionnaire is assessing the aspect related to dysphagia. Hence, The Dysphagia Quality of Life Questionnaire in Marathi (D-QOL-QM) finally comprised of 47 statements under functional, eating, psychosocial and physical section.

**Reliability**

The reliability of the test refers to the extent to which the test is likely to produce consistent ratings. The internal consistency is useful in construction of new scales and questionnaires and measures consistency and non-equivalence of different questions intended to measure the same concept. In the current study to check internal consistency reliability Cronbach's alpha coefficient was calculated. The overall Cronbach's alpha coefficient was very high ( $\alpha=0.93$ ) for the questionnaire which showed a good reliability. To check internal consistency of the sections of the questionnaire, Pearson's correlation was calculated. Total score was correlated with each section score which showed a highly significant moderate correlation for functional section (0.689) and physical section (0.643). For psychosocial section (0.854) and eating section (0.868) a highly significant high correlation was obtained. The alpha coefficient of D-QOL-QM was high and also sections had acceptable internal consistency, hence, questionnaire is found to be reliable.

**Descriptive Analysis of D-QOL-QM**

The mean and standard deviations of 4 sections (functional, eating, psychosocial and physical) and mean and standard deviations for each statement of D-QOL-QM was calculated. Mean ratings obtained by individuals with dysphagia for all statements of D-QOL-QM questionnaire is shown in Figure 1. As observed, all individuals with dysphagia had higher scores indicating poor quality of life (Figure1). On an average, participants gave a rating of 2.68 on D-QOL-QM, indicating impaired swallowing ability affecting their quality of life. Analysing the mean ratings given by individuals with dysphagia for each statement of the D-QOL-QM, it was noted that for 4 statements individuals gave extreme ratings ( $F_{unc}$ -S11,  $E_{ating}$ -S15,  $E_{ating}$ -S20,  $P_{sychSoc}$ -S33) and low ratings were given for 5 statements ( $F_{unc}$ -S5,  $E_{ating}$ -S21,  $E_{ating}$ -S27,  $P_{hysical}$ -50 and  $P_{hysical}$ -52).

The mean and SD of D-QOL-QM scores were obtained for each section and it was observed that

scores were high in all sections with maximum scores obtained for psychosocial section followed by functional and physical section. Eating section had less scores compared to other sections (Figure 2). In the functional section statements number  $F_{unc}$ -S2,  $F_{unc}$ -S8,  $F_{unc}$ -S11 showed higher ratings than other statements (Figure 3). Statements number  $E_{ating}$ -S13 and  $E_{ating}$ -S20 showed higher ratings on eating section (Figure 4). In psychosocial section statement number  $P_{sychSoc}$ -S23,  $P_{sychSoc}$ -S28,  $P_{sychSoc}$ -S33 and  $P_{sychSoc}$ -S34 showed higher ratings (Figure 5). In physical section higher ratings were shown by statement numbers  $P_{hysical}$ -S41,  $P_{hysical}$ -S42 and  $P_{hysical}$ -S55 (Figure 6).

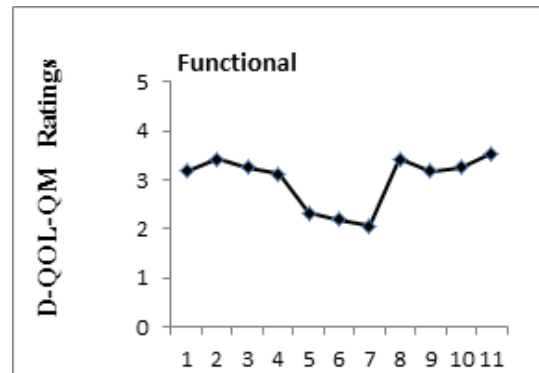


Figure 3: Shows D-QOL-QM scores for functional section

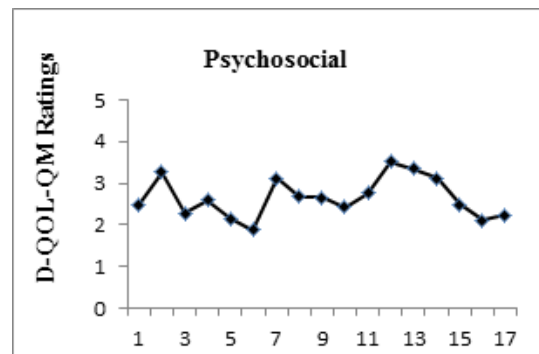


Figure 4: Shows D-QOL-QM scores for psychosocial section

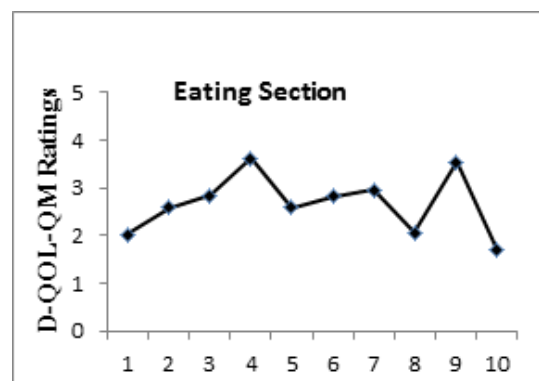


Figure 5: Shows D-QOL-QM scores for eating section

Table 2: Shows cronbach's alpha value for each statement if that is deleted

Statements	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
F <sub>unc</sub> -S5	130.58	1467.813	-.011	.930
E <sub>ating</sub> -S21	130.32	1444.673	.175	.929
P <sub>psychSoc</sub> -S26	130.63	1451.912	.170	.929
P <sub>physical</sub> -S41	130.00	1442.000	.254	.928
P <sub>physical</sub> -S42	130.47	1426.596	.356	.928
P <sub>physical</sub> -S43	130.37	1453.135	.131	.929
P <sub>physical</sub> -S44	129.63	1449.357	.122	.930
P <sub>physical</sub> -S48	129.89	1450.877	.121	.929
P <sub>physical</sub> -S49	131.21	1450.731	.466	.928
P <sub>physical</sub> -S50	131.32	1454.654	.231	.927
P <sub>physical</sub> -S52	131.85	1450.143	.165	.930
P <sub>physical</sub> -S55	129.63	1449.35	.122	.93

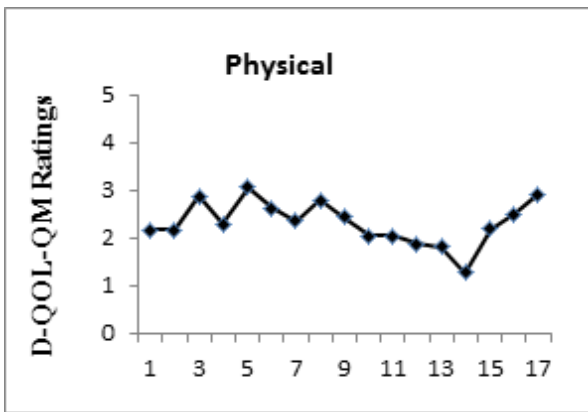


Figure 6: Shows D-QOL-QM scores for physical section

## Discussion

The developed questionnaire, D-QOL-QM, has high reliability and its subsections showed acceptable internal consistency, therefore, it's a reliable clinical tool for assessing quality of life. It is a self-perceived questionnaire based on experience of individuals with dysphagia and quality-of-life outcomes from individuals with dysphagia and their caregivers. There are valid and reliable generic tools available in western literature to assess quality of life in individuals with dysphagia. Some of the widely used generic tools for assessing quality of life are; SWAL-QOL which is a valid and reliable ( $\alpha=0.80$ ) outcome tool for monitoring treatment effectiveness (McHorney et. al., 2002; McHorney, Martin, Harris, Robbins & Rosenbek, 2006); and DHI is reliable ( $\alpha=0.94$ ), clinically efficient, patient reported outcome tool for measuring handicapping effect of dysphagia. Similar to these tools, D-QOL-QM developed in this study has good reliability ( $\alpha=0.93$ ).

D-QOL-QM finally contained 47 statements under four sections. During the process of item analysis, 8 statements were deleted and 4 statements were retained due to their high relevance to quality of life of individuals with dysphagia. Item which required deletion belonged majorly to physical section, where statements are related symptoms of dysphagia, followed by items of Eating and Functional section. Similar findings have been reported by some of the questionnaire developed in western literature. In SWAL-QOL tool, items related to bothering of symptoms (e.g. Choking while taking food) were eliminated (McHorney, Martin, Harris, Robbins & Rosenbek; 2006) and while developing DHI four items from physical section ('It takes me longer to eat a meal than it used to') were retained which were judged by the author to have high content validity or provided pertinent clinical information.

High scores obtained on D-QOL-QM by individuals with dysphagia indicate that quality of life is affected in them. It was noted that psychosocial section was maximally affected followed by functional and physical whereas eating section was less affected compared to others. Ratings given by individuals with dysphagia were analysed statement-wise for each section. Aspects of the psychosocial section which showed significant effect on individual's quality of life were; need of being alert and careful while eating; avoiding food outings and social gatherings; embarrassment of eating in public. On the functional section, quality of life was more affected on tiredness and weakness area. They also showed significant abnormality on speech and voice statements. In physical section mostly quality of life was affected due in characteristics like impaired chewing ability of individuals with dysphagia and gag while eating. They had to swallow food several times for food to go down, avoided certain kind of

food due to dysphagia and took long time to finish a meal. For eating section, quality of life was limited because individuals avoided certain kind of food due to dysphagia and took long time to finish a meal. Therefore, the results indicated that impact of psychosocial aspects on individuals life was highest compared to other sections. A study investigated impact of Idiopathic Parkinson's disease (IPD) on swallow- specific quality of life using SWAL-QOL questionnaire and aimed find relationship of swallow- specific quality of life with severity & duration of IPD and with health related quality of life measured using PDQ-39. Results showed significant relationship between SWAL-QOL and PDQ-39 which highlights existence of psychosocial sequel with swallowing impairment in IPD which suggest a possible association of swallowing, social, functional and depression (Plowman-Prine et. at., 2009) Current study also reports impaired quality of psychosocial aspects for individuals with dysphagia. Therefore, D-QOL-QM is dysphagia-specific generic tool which will help us to assess impact of dysphagia on one's quality of life.

## Conclusions

This study provides a reliable clinical tool, The Dysphagia Quality of Life Questionnaire in Marathi - D-QOL-QM, for assessing impact of dysphagia on individual's life. D-QOL-QM consists of functional, eating, psychosocial and physical sections. High scores obtained on D-QOL-QM questionnaire indicated that quality of life was affected in individuals with dysphagia and psychosocial section was maximally affected followed by functional and physical section whereas eating section was less affected. Quality of life is a subjective self-perceived measure so impact of a dysphagia cannot be generalized as it varies from person to person, therefore, the developed questionnaire will help us in assessing quality of life in individuals with dysphagia in Indian scenario. As number of participants considered in this study was limited one need to be careful in interpreting and generalizing the findings of this study. Future research can be done to assess quality of life in individuals with dysphagia with varied aetiologies on a large sample considering and can be used for documenting treatment outcome in dysphagia management. D-QOL-QM can be translated in other Indian languages for clinical utility.

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## Appendix I

## Dysphagia-Quality of life Questionnaire in Marathi

## (D-QOL-QM)

Name:  
Age\Sex  
Address:

Date:  
Registration no.  
Referred from:  
Occupation:

Diagnosis:  
Medical History:  
Mode of feeding: Oral / Non-oral, If non-oral Specify

**Instructions:** This questionnaire will collect information related to your swallowing difficulties which affects different areas of your life. Kindly remember that all statements are related only to swallowing problems faced by you. Please read or listen to each statement carefully and give appropriate answers depending on what you have felt in last one month. You have to give your responses in the space provided for each statement using the following response options;

/prəisadə/	/kədhī:tfnah/	/kvətʃit̪/	/k@dhi:k@dhi:/	/k <sup>h</sup> upda/	/dʒəvədʒəvəlnəhmi/
/guŋsənk <sup>h</sup> ja/	1	2	3	4	5
Response	Never	Hardly ever	Sometimes	Often	Almost always
Scoring	1	2	3	4	5

**Responses are given by:** Self/Family members/Assisted by family members/others

A. Functional Section		/prəisad/
		Response
1	/madʒ <sup>h</sup> ja/ /gɪŋjatʃa/ /k <sup>h</sup> anjatʃa/ /tras/ /hat̪ŋe/ /k <sup>h</sup> up/ /kət <sup>h</sup> ŋ/ /dzate/. It is very difficult to handle my swallowing /eating problem.	
2	/gɪŋjatʃa/ /k <sup>h</sup> anjatʃa/ /trasamule/ /madʒ <sup>h</sup> ja/ /dʒɪvnavar/ /pəŋgam/ /hoŋ/ /ahe/. Due to my swallowing/eating problem my life is getting affected.	
3	/madʒ <sup>h</sup> ja/ /gɪŋjatʃa/ /k <sup>h</sup> anjatʃa/ /trasamule/ /mɪ/ /tɪvɪ/ /pahət̪ana/ /dʒeu/ /fant̪/ /dz <sup>h</sup> op/. Due to my swallowing / eating problem I cannot watch TV while eating	
4	/madʒ <sup>h</sup> ja/ /gɪŋjatʃa/ /k <sup>h</sup> anjatʃa/ /trasamule/ /məla/ /fant̪/ /dʒ <sup>h</sup> op/ /jɛŋ- jas/ /tras/ /hoto/. Due to my swallowing / eating problem I have difficulty falling asleep.	
5	/madʒ <sup>h</sup> ja/ /gɪŋjatʃa/ /k <sup>h</sup> anjatʃa/ /trasamule/ /məla/ /dəmɭjasark <sup>h</sup> e/ /və/ /t <sup>h</sup> akɭjasark <sup>h</sup> e/ /vatət̪e/. Due to my swallowing / eating problem I feel tired and exhausted.	
6	/madʒ <sup>h</sup> ja/ /gɪŋjatʃa/ /k <sup>h</sup> anjatʃa/ /trasamule/ /məla/ /dəmɭjasark <sup>h</sup> e/ /dzaŋəvto/. Due to my swallowing / eating problem I feel weak.	
7	/madʒ <sup>h</sup> ja/ /gɪŋjatʃa/ /k <sup>h</sup> anjatʃa/ /trasamule/ /lokana/ /maðz <sup>h</sup> ə/ /bolŋə/ /tras/ /hoto/. Due to my swallowing / eating problem, people have difficulty understanding my speech.	
8	/madʒ <sup>h</sup> ja/ /gɪŋjatʃa/ /k <sup>h</sup> anjatʃa/ /trasamule/ /məla/ /bol̪t̪ana/ /tras/ /hoto/. Due to my swallowing / eating problem I have trouble speaking.	
9	/madʒ <sup>h</sup> ja/ /gɪŋjatʃa/ /k <sup>h</sup> anjatʃa/ /trasamule/ /madʒ <sup>h</sup> a/ /avadz/ /bəd̪əlla/ /ahe/. Due to my swallowing / eating problem my voice has changed.	
10	/madʒ <sup>h</sup> ja/ /gɪŋjatʃa/ /k <sup>h</sup> anjatʃa/ /trasamule/ /mɪ/ /dʒast̪ə/ /vel/ /bolu/ /fəkət̪/ /nahɪ/. Due to my swallowing / eating problem I am unable to talk for long time.	

Section Score (add scores of section A)		A =
Section Average Rating		A ÷ 10 =
<b>B. Eating Section</b>		/prɑtʃɑd/ (Response)
11	/mɑdʒʰjɑ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑtʃɑ/ /trɑsɑmule/ /bərətʃ/ /dɪvɑs/ /mɪ/ /dʒevtə/ /vels/ /bolu/ /fəkət/ /nɑhɪ/. Due to my swallowing /eating problem most days I don't bother I eat or not	
12	/mɑdʒʰjɑ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑtʃɑ/ /trɑsɑmule/ /bərətʃ/ /dɪvɑs/ /mɪ/ /kɑhɪ/ /prəkɑrtʃe/ /kʰɑdəpədɑrtʰə/ /tɑltə/ /tɑlt/. Due to my swallowing / eating problem I avoid certain kind of food.	
13	/mɑdʒʰjɑ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑtʃɑ/ /trɑsɑmule/ /mɪ/ /kəmi/ /kʰɑtə/ /kʰɑtə/. Due to my swallowing / eating problem I eat less	
14	/mɑdʒʰjɑ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑtʃɑ/ /trɑsɑmule/ /mələ/ /dʒvəj/ /səmpəvɪje/ /kʰhɪj/ /dzɑte/ Due to my swallowing / eating problem I have difficulty in finishing a meal	
15	/mɑdʒʰjɑ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑtʃɑ/ /trɑsɑmule/ /mɪ/ /tʰode/ /tʰode/ /ənnə/ /kʰup/ /veles/ /kʰɑtə/ /kʰɑtə/. Due to my swallowing / eating problem I eat small quantity of meals several times.	
16	/mɑdʒʰjɑ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑtʃɑ/ /trɑsɑmule/ /mələ/ /kʰɑjɑs/ /kʰup/ /veləs/ /kʰɑtə/ /kʰɑtə/. Due to my swallowing / eating problem it takes long time for me to eat.	
17	/mɑdʒʰjɑ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑtʃɑ/ /trɑsɑmule/ /mələ/ /bʰuk/ /əsɪ/ /təɪ/. Due to my swallowing / eating problem although I feel hungry but do not eat.	
18	/mɑdʒʰjɑ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑtʃɑ/ /trɑsɑmule/ /mələ/ /mɑdʒʰɑjɑsɑtʰɪ/ /jogjə/ /ənnə/ /nɪvədɪjɑs/ /əvgʰəd/ /dzɑte/. Due to swallowing / eating problem I have difficulty selecting food items I can eat.	
19	/mɑdʒʰjɑ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑtʃɑ/ /trɑsɑmule/ /gʰərətɪjɑ/ /vjetɪnɑ/ /mɑdʒɑtsɑtʰɪ/ /svəjəmpɑk/ /bənəjɑs/ /kəʰtɪj/ /dʒɑte/ Due to my swallowing / eating problem my family has trouble preparing food for me.	
20	/mɑdʒʰjɑ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑtʃɑ/ /trɑsɑmule/ /mɪ/ /svətəhɑ/ /dʒvəj/ /kəru/ /fəkət/ /nɑhɪ/. Due to my swallowing / eating problem I am not able to feed myself.	
Section score (add scores of section B)		B =
Section Average Rating		B ÷ 10=
<b>C. Psychosocial Section</b>		/prɑtʃɑd/ (Response)
21	/mɑdʒʰjɑ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑtʃɑ/ /trɑsɑmule/ /mələ/ /kʰɑvese/ /vɑtət/ /nɑhɪ/. Due to my swallowing / eating problem I don't feel like eating	
22	/mɑdʒʰjɑ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑtʃɑ/ /trɑsɑmule/ /mələ/ /kʰɑjɑtʃjɑ/ /mɑdʒɑ/ /jetɪ/ /nɑhɪ/. Due to my swallowing / eating problem I don't enjoy eating	
23	/gɪlɪjɑtʃjɑ/ /ɑjɪ/ /kʰɑjɑtʃɑ/ /trɑs/ /əsɪjɑmule/ /mɪ/ /kʰɑjə/ tɑltə/ /tɑlte/. Due to my swallowing /eating problem I avoid food	
24	/mɑdʒʰjɑ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑtʃɑ/ /trɑsɑmule/ /mələ/ /ənnə/ /swɑsnəlɪket/ /dʒɑjɑtʃɪ/ /bʰɪtɪ/ /vɑtəte/. Due to my swallowing / eating problem I fear food will enter my wind pipe	
25	/mɑdʒʰjɑ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑtʃɑ/ /trɑsɑmule/ /mələ/ /vəjfaljə/ /jetə/. Due to my swallowing / eating problem I feel depressed.	
26	/mələ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑ/ /trɑsɑmule/ /mələ/ /betʃənm/ /vɑtəte/. Due to my swallowing / eating problem I feel nervous while eating.	
27	/mələ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑ/ /trɑsɑmule/ /mələ/ /kʰɑtɑnɑ/ /rɑg/ /jetə/ Due to my swallowing / eating problem I get angry while eating.	
28	/mɑdʒjɑ/ /gɪlɪjɑtʃjɑ/ /kʰɑjɑ/ /trɑsɑmule/ /mɑdʒjɑ/ /ɑtməvɪfvas/ /mələ/ /kəmi/ /vɑtəte/.	

	Due to my swallowing / eating problem I have low self-confidence.	
29	/madʒja/ /gɪŋjatʃja/ /kʰaŋja/ /ʈrasamule/ /məla/ /madʒa/ /ʃvas/ /kondʒ- jatʃi/ /bʰɪʈi/ /vatəte/.	
	Due to my swallowing / eating problem I fear I 'll stop breathing	
30	/madʒja/ /gɪŋjatʃja/ /kʰaŋja/ /ʈrasamule/ /məla/ /kʰatana/ /kaldʒi/ / gʰjavɪ/ /lagte/	
	Due to my swallowing / eating problem I have to be careful while eating	
31	/madʒja/ /gɪŋjatʃja/ /kʰaŋjatʃja/ /ʈrasamule/ /məla/ /kʰaŋjatʃi/ /bʰɪʈi/ /vatəte/	
	Due to my swallowing / eating problem i fear eating	
32	/madʒja/ /gɪŋjatʃja/ /kʰaŋja/ /ʈrasamule/ /səmadʒɪk/ /kamas/ /dʒaŋjas/ /talto/	
	Due to my swallowing / eating problem I avoid social gatherings	
33	/madʒja/ /gɪŋjatʃja/ /kʰaŋja/ /ʈrasamule/ /mi/ / dʒewjjasatʰi/ /baher/ /dzatʃ/ /nahɪ/	
	Due to my swallowing / eating problem I do not go out to eat	
34	/madʒja/ /gɪŋjatʃja/ /kʰaŋja/ /ʈrasamule/ /məla/ /səmadʒatun/ /svəthala/ /wəgəŋjasarkʰe/ /vatəte/	
	Due to my swallowing / eating problem I feel excluded from society	
35	/madʒja/ /gɪŋjatʃja/ /kʰaŋja/ /ʈrasamule/ /madʒja/ /kutumbatʃ/ /və/ /mɪʈranmədʰe/ / madʒʰi/ /bʰumika/ /bədələi/ /ahe/	
	Due to my swallowing / eating problem my role with my family and friends has changed.	
36	/madʒja/ /gɪŋjatʃja/ /kʰaŋja/ /ʈrasamule/ /kʰajla/ /ŋjʊŋəndə/ /vatəto/ Due to my swallowing / eating problem I am embarrassed to eat in public	
	Section score (add scores of section C)	C =
	Section Average Rating	C / 16=
	<b>D. Physical Section</b>	/prətsad/ (Response)
37	/kʰatana/ /məla/ /sarkʰa/ /tʰəska/ /jetʃ/ /əsljamule/ /məla/ /kʰaŋe/ /kəŋŋ/ /dzate/	
	Because while eating I cough a lot, I find it difficult to eat	
38	/pɪtana/ /məla/ /sarkʰa/ /tʰska/ /jetʃ/ /əsljamule/ /məla/ / gɪŋe/ /kəŋʰŋ/ /dzate/.	
	Because while swallowing I cough a lot, I find it difficult to drink	
39	/madʒa/ / ʃavŋatʃja/ /ʈrasamule/ /məla/ /kʰaŋe/ /əvgʰəd/ /dzate/	
	Because of difficulty in chewing I find it difficult to eat.	
40	/sarkʰa/ / gʰsa/ / kʰkərljamule/ /məla/ /kʰaŋe/ /kɪva/ /gɪŋe/ /əvgʰəd/ /dzate/	
	Because I clear my throat constantly ,I find it difficult to eat / swallow	
41	/təndat/ /sarkʰe/ /ənə/ /ʃɪktun/ /rahiljamule/ /kʰaŋe/ /kətsuper hŋ/ /dzate/	
	Because of food sticking in mouth I find it difficult to eat	
42	/gʰafatʃ/ /ənə/ /ʃɪktun/ /rahiljane/ /məla/ /gɪŋe/ /əvgʰsuper həd/ /dzate/	
	Because of food sticking in throat I find it difficult to swallow	
43	/madʒʰja/ /gɪŋjatʃja/ /kʰaŋjatʃja/ /ʈrasamule/ /ənə/ /təndatun/ /baher/ /pədtə/.	
	I find it difficult to eat because, food spills from mouth.	
44	/məla/ /kʰaŋjatʃja/ /dʌkʰte/.	
	I feel pain while eating \drinking	
45	/madʒʰja/ /gɪŋjatʃja/ /kʰaŋjatʃja/ /ʈrasamule/ /məla/ /gʰafatʃ/ /kahitari/ /ədəkʌjasarkʰe/ /vatəte/.	
	Due to my swallowing / eating problem I feel obstruction in throat while eating.	
46	/madʒʰja/ /gɪŋjatʃja/ /kʰaŋjatʃja/ /ʈrasamule/ /məla/ /paŋjatʃi/ /kəmtəta/ /vatəte/	
	Due to my swallowing / eating problem I feel dehydrated.	
47	/madʒʰja/ /gɪŋjatʃja/ /kʰaŋjatʃja/ /ʈrasamule/ /ənə/ /kʰali/ /dʒajjasatʰi/ /məla/ /kʰup/ /vel/ /gilave/ /lagte/	

Due to my swallowing problem I need to swallow food several times for food to go down

Section Score (add scores of section D)	D =
Average Rating	D ÷ 11 =

**Scoring:**

Total Score = A+B+C+D =

Overall Average Rating = Total Score ÷ 47 =

**Interpretation:**

Overall Quality of Life:

Functional Section:

Eating Section:

Psychological Section:

Physical sections

**Remarks**