

# Short message service prompted mouth self-examination in oral cancer patients as an alternative to frequent hospital-based surveillance

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## Abstract

**Introduction:** Oral squamous cell carcinoma (OSCC) are amongst commonest cancer in the Indian sub-continent. After treatment, these patients require frequent followup to look for recurrences/second primary. Mouth Self Examination (MSE) has a great potential in all levels of prevention of oral cancer. However, the compliance to self-examination has been reported as poor. Mobile phone is a cheap and effective way to reach out to people. Short Message Service (SMS) is extremely popular can be a very effective motivational and interactive tool in health care setting. **Methodology:** We aimed to identify in adequately treated OSCC patients, the influence of health provider initiated SMS on the compliance to the MSE and to establish the efficacy of MSE by comparing patients' MSE interpretation via replies to the SMS with that of the experts' opinion on clinical examination status during follow up. **Conclusion:** We conclude that MSE can be very useful in adequately treated OSCC patients for evaluating disease status. All treated OSCC patients must be adequately educated for MSE as an integral part of treatment & follow-up protocol by the health provider facility. Health provider generated SMS reminders do improve motivation and compliance towards MSE but don't seem to reduce dropouts in follow up for large and diverse population like that in India.

**Key words:** Mouth self-examination, oral squamous cell carcinoma, short message system, surveillance

## Introduction

Oral squamous cell carcinoma (OSCC) is a tobacco-related major health problem. It is seen more commonly in Southeast Asia, particularly in the Indian subcontinent. OSCC is the most common cancer and is the major cause of cancer-related death in Indian men.<sup>[1,2]</sup> Even after adequate treatment, there are chances of recurrences in patients of OSCC due to field cancerization, recurrences, and second primaries. Hence, these patients require frequent follow-up visits to the hospital.<sup>[3,4]</sup> OSCC is especially common in low socioeconomic strata. These patients are often poor and are unable to make frequent long distance travel from their homes to cancer care facilities leading to big drop out in the follow-up. Many patients, therefore, come back with advanced recurrences.

Mouth self-examination (MSE) has a great potential in all levels of prevention of oral cancer. Its use as "a screening modality" has been shown to be very effective in population at high risk for oral cancer. However, the compliance to self-examination hitherto has been reported as very poor.<sup>[5-11]</sup>

Mobile phone is a cheap and effective way to reach out to people. The use of mobile phones has increased exponentially in the recent years. Its growth has been so tremendous that even in a country like India, with a vast rural population; there are about 1034.25 million mobile phone users. Overall teledensity of mobile phone users is 91.35 per 100 users.<sup>[12]</sup> The increase in mobile phone teledensity has been driven mainly by low cost of handsets, low tariffs, and ultimately the ease of using a phone as well as supply side factors. Short message service (SMS) is extremely popular in India that allows the interchange of short texts with cost less than half a cent per SMS. SMS can be a very effective and cost effective motivational and interactive tool in any tertiary health-care setting.<sup>[11,12]</sup>

Therefore, we decided to evaluate the effect of SMS reminders on the compliance of posttreatment OSCC patients for MSE

and to establish its efficacy by comparing patients' MSE interpretation through SMS to the expert clinical examination for detecting recurrences.

## Materials and Methods

This study was a prospective observational feasibility study which was approved by the Institutional Review Board. All OSCC patients who had successfully completed their treatment and were visiting the head and neck oncology services regularly for follow-up (December 2011-April 2012) were screened for eligibility. Possession of cell phone and ability to use the SMS were prerequisites for inclusion into the study. Illiterate patients who had a literate, responsible caregiver, competent as per the above criteria were also included as participants with due permission and consents. Participants not willing for regular follow-up at the hospital were excluded from the study. Patients with <2 finger interincisal mouth opening were excluded from the study.

All participants were provided with written information sheets of the study and informed consents. Demographic details such as age, gender, level of education, and mobile numbers were recorded.

The participants were educated about MSE by a team of trained head and neck oncologists, using a PowerPoint presentation that depicted detailed procedure of MSE, normal oral mucosal appearance, and cancerous, precancerous lesions through high-resolution photographs. The patients were then asked to show how to perform MSE themselves in front of a mirror in good illumination assisted with a torch light held in the other hand, by proper retraction and palpation of all areas of the oral cavity (e.g., buccal mucosa, tongue, labial mucosa, floor of mouth, gingivae, palate, and faucial pillars) to clear out doubts if any. All patients were alerted to carefully look for any change in appearance and feel of their existing oral mucosa.

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All participants were instructed for doing MSE at least once every day.

At the time of initiation, an introductory SMS from a preinformed and specific mobile number was sent to all participants for confirmation of the SMS delivery. The message which was sent was – Thank you for participation. Tobacco use causes cancer. Please reply “Y” on delivery of this message. They were asked to reply immediately to ensure their competence in using the system. This educative and trial SMS was not included in the final analysis. Status interrogatory messages (SI) for encouraging MSE along with a question for patients’ own interpretation of examination regarding disease status (any new oral lesion) were sent 1 week before scheduled follow-up visit. The SI message which was sent was – Examine your mouth daily. Have you noticed any new ulcer/patch/swelling in your mouth? If “No,” reply “N.” If “Yes,” reply “Y.”

These SMSs were expected to be answered in a particular way as stated in the SI, anytime before their scheduled follow-up visit. Patients were asked to reply to the particular SI message only once [Figure 1].

All patients were examined as per the standard hospital protocol, and their clinicians’ assessment results were recorded. Examining clinicians were not informed about patients’ own perception of MSE. Those with clinically established recurrent disease were not sent further SI messages. Improper replies were not considered in analysis. Repetitive replies were included only once in the analysis. Data were tabulated and analyzed using SPSS version 16 (IBM Corp. Armonk, New York, USA).

## Results

A total of 206 adequately treated OSCC patients were included in this study. Demographic details of the patients are given in Table 1.

A total of 228 SI messages were sent 1 week before the scheduled follow-up visit (22 patients were messaged twice during the study period as per their follow-up schedule, hence the figure is higher than 206). One hundred and sixty-eight message replies were received in response to the SI messages response rate was 73.68%. SI message replies as well as respective clinician’s responses were available in 143 (62.72%). Thirty-nine (17.11%) visits to the hospital for follow-up were made without reply to the SI message. Most common reason for not replying was that the patients forgot to do so ( $n = 38$ ), other reason being, change of telephone number ( $n = 1$ ). Replies to 25 (10.96%) SI messages were available without a clinician’s expert comment in view of patient not visiting the hospital. Twenty-one (9.21%)

SI messages did not have replies nor follow-up visits for clinical assessment. Thus, sixty (26.32%) SI messages did not have a reply and 46 SI (20.18%) did not have clinicians’ assessments [Table 1].

Patients who replied as having disease and found to be normal after clinical examination had mucosal redness or ulcers due to mucositis and xerostomia ( $n = 22$ ) (93%) and traumatic/aphthous ulcers ( $n = 2$ ) (7%). Out of three patients who reported to have disease and were found to have a recurrence on clinical examination and biopsy, one had local recurrence whereas 2 had locoregional (primary + neck) recurrences.

We also studied the influence of age, gender, and level of education on clinical concordance by a univariate analysis using Chi-square test [Table 1]. We found that, among these, the level of education was the only significant factor for clinical concordance and compliance to MSE ( $P = 0.039$ ).

## Discussion

OSCC is among the most common cancers in the world. It is seen more often in the Indian subcontinent.<sup>[1,2]</sup> This is due to excessive use or chewable form of tobacco in this part. Regardless of the disease stage, OSCC patients have a high risk of recurrences due to field cancerization and possibility of developing secondary tumors. These patients, therefore, require frequent follow-up visits to the hospital.<sup>[3,4]</sup> OSCC is especially common in patients from lower and middle socioeconomic strata where ignorance, poverty, and long distances from dedicated cancer care facilities lead to big drop out in the follow-up. Many patients, therefore, come back with recurrences in advanced stages.

MSE has been considered an effective strategy in screening high-risk population but has questionable compliance rates.<sup>[6-9]</sup> SMS is a low cost, easy to access, and interactive modality of mobile phone.

Hence, we aimed at checking the effectiveness of SMS in encouraging patients of adequately treated OSCC to perform MSE. The efficacy of such an examination for detecting disease was compared with examination done by a trained head and neck oncologist.

### Effectiveness of short message service for mouth self-examination

Compliance to MSE has been varied; with one study<sup>[7]</sup> reporting compliance of 36% whereas another<sup>[6]</sup> reporting compliance of 87%. In our study, we received 168 replies to the SI sent which can be considered as a surrogate indicator to MSE, thus showing a response rate of 73.6%.

### Efficacy of mouth self-examination

SMS response about MSE as well as evaluation of oral cavity by an expert was both available in 143 (62.72%) situations. In the present study, we found that, in detecting recurrence/disease, MSE had a sensitivity of 100% and specificity of 82.85%. We had utilized verbal instructions, actual demonstrations, PowerPoint presentations and interactive sessions to resolve queries. Besides these, SMS was sent before the follow-up visit. A study was conducted by Furquim *et al.* for identifying efficacy of MSE in patients with Fanconi’s anemia.<sup>[11]</sup> They reported a sensitivity of 43% and specificity of 44%. They had used verbal instructions

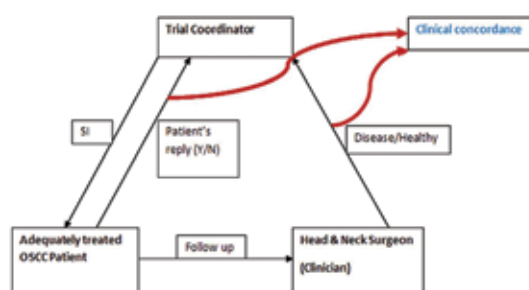


Figure 1: Study algorithm

**Table 1: Sample demographics, study fact sheet, results, and demographic factors influencing the accuracy of mouth self-examination and tendency for reply/nonreply**

Parameter recorded	Category	Total number (%)
Age (years)	Up to 30	8 (3.9)
	31-50	105 (51)
	51-70	91 (44.1)
	71 above	2 (1)
Gender	Male	181 (87.9)
	Female	25 (12.1)
Level of education	Illiterate (with educated and competent caregiver)	4 (1.9)
	Primary school (4 years of schooling)	4 (1.9)
	Secondary school (5-10 years of schooling)	56 (27.2)
	Senior secondary school (10+2 years of schooling)	32 (15.5)
	Graduate	82 (39.8)
	Postgraduate	28 (13.6)
<b>Study facts sheet and results</b>		
Number of patients		206
Total SI sent		228
Total number of valid replies received		168 (reply rate - 73.68%)
Total number of replies to particular SI and clinicians' response for the same		143 (62.72%)
Those who replied as being normal and found "normal" after clinical follow-up		116 (81.12%)
Those who replied as being normal and found to have disease after clinical follow-up		0
Those who replied as having disease and found "normal" after clinical follow-up		24 (16.78%)
Those who replied as having disease and found to have the same after clinical follow-up		3 (2.09%)
<b>Clinical concordance</b>		
Sensitivity		100%
Specificity		82.85%
<b>Demographic factors influencing the accuracy of MSE (clinical concordance)</b>		
		<b>P</b>
Age		0.904 (not significant)
Gender		0.209 (not significant)
Education		0.039 (significant)
<b>Demographic factors influencing tendency to reply/nonreply to the SI</b>		
		<b>P</b>
Age		0.086 (not significant)
Gender		0.052 (not significant)
Level of education		0.199 (not significant)

MSE=Mouth self-examination, SI=Status interrogatory

and charts as instruction medium for the patients. While Elango *et al.*<sup>[9]</sup> who utilized health workers to educate the patients with the help of brochure/leaflet reported poor sensitivity (18%) and high specificity (99%). Scott *et al.*<sup>[7]</sup> used pamphlets and reported a sensitivity of 33% and specificity of 54%.

We believe that a very high sensitivity, specificity, and better compliance rates in our study sample can be explained by the following reasons:

1. Unique sample of treated OSCC patients who have experienced and lived through the signs and symptoms of the disease before and hence have better knowledge of hospital experience and awareness of risk factors and better motivation toward MSE
2. In previous studies, MSE technique was informed to the participants using a brochure/leaflet by health workers/students whereas, in the present study, MSE technique was instructed by a head and neck oncologist giving all customized and technical information to individual patients with PowerPoint Presentation using high-resolution images of oral precancerous and cancerous lesions, practical demonstration of MSE and allowing ample opportunity to clear doubts if any

3. Patients in our study were made aware of appearance of their oral mucosa and were instructed to respond to any change in appearance or *de novo* lesions using MSE leading to possibly better accuracy in identifying positive lesions
4. A small sample size ( $n = 206$ ) OSCC patients as compared to other large population study groups and cross-sectional feasibility nature of the study.

We studied the influence of demographic factors on accuracy of MSE. On univariate analysis, MSE accuracy in our study was found to be significantly related only to the participants' level of education ( $P = 0.039$ ). Elango *et al.*<sup>[9]</sup> observed that the awareness of risk factors was directly proportional to the level of education and inversely proportional to the prevalence of risk factors. It was also observed that participants of older age group, who are at increased risk of developing oral cancer, had a relatively lower compliance to perform MSE.

Majority of our study participants were young and middle age group ( $n = 113$ ) (54%) and literate which might have improved adherence to MSE. Although age ( $P = 0.904$ ) was not found to be a statistically significant factor for accuracy of MSE.



In the present study, none of the four illiterate participants with competent caregiver either replied to SI or followed-up, thus underlining the importance of literacy on awareness and compliance to MSE [Table 1]. In a study conducted in Australia, it was found that patients who felt themselves subject to susceptibility, severity of disease, and benefits of examination were more likely to perform MSE.<sup>[13]</sup>

#### Use of short message service as motivational and interactive tool

Information technology is rapidly advancing and making its way into many health-care settings. Mobile phone has revolutionized and individualized access to information sharing. In most of the developing countries, in the past decade, telecommunication sector has changed most drastically due to the advent of low cost, easily accessible, convenient, and user-friendly mobile phones and India has one of the lowest mobile tariffs in the world.

In the present study, we attempted to study the effect of health-care provider generated SMS on MSE compliance and the demographic factors which may influence the tendency to reply to such a message. However, we could not find any particular factor influencing the likelihood of replying or not replying the SMS.

In a study on preferred mode of electronic reminders for cancer prevention, Greaney *et al.*<sup>[14]</sup> observed that SMS may not be favorite means of communication for older ages and in illiterate participants. Inability to read and write in English is also an inherent limitation for the use of SMS reminders. In our study, a total of sixty (26.32%) SIs were not replied. We feel that a sizable number of participants ( $n = 93$ ) (45%), who were older than 50 years or more, may not have SMS as favorite means of communication hence dropouts in replies to SI can be hypothesized. However, the high compliance rate to MSE (upwards of 70%) and high sensitivity of MSE can be partly attributed to the use of mobile phone-based SI messages. In a study on improving breast self-examination (BSE) in working women in New Delhi, India, text messages were used to remind women to do their monthly breast self-examination, and after first 2 months of sending SMS reminders, the practice of BSE improved significantly. The authors inferred that SMS on the mobile was perceived by the participants as an insistent alert requiring instant action so that health issue if any can be addressed. Similarly, the use of SMS for health awareness, treatment, and health-related information sharing has been tried successfully across the globe.<sup>[15]</sup>

A matter of concern, however, is the dropout in the follow-up visits. Despite SMS reminders, nearly 46 (20.18%) SIs were without clinicians' follow-up examination.

#### Limitations

This is an observational cross-sectional feasibility study of a small sample for a short duration. The MSE sensitivity rate of 100% is due to highly selective population of adequately treated OSCC patients. Application of similar protocol in larger populations may require several modifications in designing and execution. Furthermore, easier, advanced, and cheaper interactive technology may be available with ever-changing mobile phone use, especially after the advent of smart phones and androids. Furthermore, this study does not take into

account patients' presenting disease status, treatment received, and time elapsed since completion of treatment.

#### Conclusion

The present study indicates usefulness and efficacy of MSE in adequately treated OSCC patients for evaluating disease-free status and recurrences. SMS reminders in the form of SI messages do improve motivation and compliance of toward MSE. All treated OSCC patients must be adequately educated for MSE as an integral part of treatment and follow-up protocol by the health provider facility. However, health provider generated SMS do not seem to reduce dropouts in follow-up for a large and diverse population like India. Simpler yet more interactive technology needs to be developed and tested to safely customize hospital-based visits in treated OSCC patients.

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#### Conflicts of interest

There are no conflicts of interest.

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