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Prevalence of dyspnoea and usage of opioids in managing dyspnoea in advanced cancer patients: a longitudinal observational multi-centre study from India

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Clinical Study

Abstract

Context: Breathlessness is one of the devastating symptoms experienced by patients with advanced cancer and can be very challenging to manage.

Objectives: To find the point prevalence of dyspnoea in advanced cancer patients presenting to palliative care out-patient clinics, and the usage of opioids in palliation of dyspnoea.

Methods: We conducted a prospective observational study among all consecutive patients presenting to the outpatient clinics of six cancer centres in India from different parts of the country. In addition to routinely documented demographic and clinical data from patient charts, study investigators collected information on the Edmonton Symptom Assessment System, Cancer Dyspnoea Scale (CDS) and European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire Core 15 Palliative Care. We calculated the prevalence of dyspnoea and documented the usage of opioids in palliation of dyspnoea using tests of differences across patient characteristics.

Results: Between May 1, 2019, and April 30, 2020, 5,541 patients were screened for eligibility, and 288 were enrolled (48 patients from each of the six centres). We analysed the data of 288 patients, of which 36.4% had dyspnoea, with 28.5% with moderate to a severe degree (>4/10). Tiredness and loss of appetite were found to have associations with dyspnoea which were statistically significant on multivariate analysis. Standard palliative care management and routine usage of opioids preceded improvement in dyspnoea scores, CDS scores and quality of life scores throughout 7 days.

Conclusion: Dyspnoea is a common symptom in advanced cancer patients, presenting to outpatient clinics, and routine documentation of dyspnoea with appropriate usage of opioids helps in mitigation.

Key message

The article suggests that breathlessness is a common problem in advanced cancer patients and opioid prescription preceded symptom improvements in such patients.

Keywords: *dyspnoea, prevalence, cancer, opioids*

Background and rationale

Dyspnoea or breathlessness is an uncomfortable and subjective feeling of breathing difficulty, which may vary in character and intensity for individual patients. This is emphasised by the consensus definition of the American Thoracic Society and it also suggests that this experience may be influenced and individualised by various physiological, psychosocial, behavioural and environmental factors and their interactions [1].

Dyspnoea is one of the commonly reported symptoms in patients with metastatic cancers and the prevalence is higher in patients with advanced malignancies, especially towards the end of life [2, 3]. Progressive worsening of dyspnoea in a patient with advanced metastatic cancer is one of the markers of poor prognosis [4]. In a previous study in our centre, we found that the prevalence of dyspnoea in advanced cancers is as high as 44.37% [5]. The symptoms in cancer patients are often compounded with other symptoms and present in clusters. Some of the common symptoms that cluster with dyspnoea are fatigue, anxiety and depression, loss of overall wellbeing and functionality, leading to poor quality of life and higher caregiver burden [6, 7]. This also has major implications in terms of further patient-care, disease management, treatment, outcomes and survival [8, 9].

The clinical prevalence, quality and management of dyspnoea vary, and being a symptom, it is not measured often, leading to little data on this [10]. Dyspnoea can be highly subjective; thus, measurement requires asking the patient. In this study, participating palliative care units had existing processes to assess unidimensional assessments of dyspnoea for all outpatients as reported in a small sample from our clinic in a previous study [5]. In this study, we report the extent of the burden of dyspnoea in terms of its prevalence among a large sample of patients with advanced cancer in multiple regional centres across India.

Methods

Study population and methodology

We conducted a prospective observational multicentric study over 1 year between 2019 and 2020 in six high volume cancer centres from different regions of India. Tata Memorial Hospital (Mumbai) was the lead research site, and the others were Acharya Harihar Regional Cancer Centre (Cuttack), Homi Bhabha Cancer Hospital & Research Centre (Visakhapatnam), Shri Siddhivinayak Ganapati Cancer Hospital (Miraj), Dr. B.R.A Institute-Rotary Cancer Hospital – All India Institute of Medical Sciences (Delhi) and the Gujarat Cancer & Research Institute (Ahmedabad).

Data were collected in the palliative medicine outpatient clinics by the study investigators. The average time for completion of the protocol was 15 minutes. Study participants were adults with advanced cancer who have been informed of their diagnosis and are well enough to complete the questionnaire. Any participants who were suffering from severe mental or cognitive disorders, and with potentially curable diseases referred for early palliative care were excluded.

Consecutive patients with advanced cancer referred to the outpatient clinics of the palliative care departments, and those who satisfy the eligibility criteria were considered for the study. Positive screened subjects were explained about the study and study procedure in a language they best understand. Participants were given adequate time to consider participation and decide. The Participant Information Sheet was given to them, and all questions were clarified to their satisfaction. Consent was taken by the Principal or Co-investigators of the participating

institutions. In case of non-participation, the reason for non-participation was recorded and routine care was offered. At the participating centres, routine palliative care is provided by specialised palliative medicine multidisciplinary team of physicians, nurses, rehabilitation therapists and social workers who coordinate care that focuses on the patient and family's individual needs. The goal of such care is to provide the patient and their family with the best quality of life for as long as possible by assisting with the physical, emotional, social and spiritual stresses associated with life-limiting illness [11]. During the study, clinicians were able to start, adjust or stop other treatments for dyspnoea as per standard of practice according to clinical judgment. The study continued till the recruitment of a minimum sample size. The baseline data were recorded at presentation to the palliative care outpatient clinic. Those patients who were started on opioids as pharmacotherapy for breathlessness management were followed up on days 1, 3 and 7 to record the prescribing patterns and change in breathlessness scores.

Study variables

On the day of study enrolment (day 0), data were collected from a chart review of routinely collected variables like age, sex, place of residence, family income (per month), educational status, contact number, marital status, primary caregiver, primary cancer diagnosis, cancer stage (at assessment), date of diagnosis of cancer, sites of metastasis, comorbidities (if any), treatment received for primary cancer, Eastern Cooperative Oncology Group score [12], symptom assessment on the Edmonton Symptom Assessment System (ESAS) [13, 14], current medications, and dosages. Two additional research questionnaires were used: Cancer Dyspnoea Scale (CDS) [15] and European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire Core 15 Palliative Care (EORTC QLQ-C15-PAL) [16] (details in Appendices). Follow-up, data were recorded on ESAS and CDS on day 1 and day 3 to record changes in symptom scores. On day 7, ESAS, CDS and EORTC QLQ-C15-PAL were recorded for change in symptoms and quality of life scores.

Statistical considerations

Calculation of minimal sample size was based on literature citing the improvement in dyspnoea scores in advanced cancer patients with morphine and study site-specific adjustments for data variability. The predicted standard deviation of the Visual Analogue Scale (VAS) from the literature is 16 mm (the VAS ranges from 0 to 100 mm) [17, 18]. Thus, a minimum of 48 participants per centre could provide 80% power to detect a 10-mm difference in the scale, with α of 0.05, allowing for a 20% dropout rate [19].

We analysed data with descriptive statistics to find the point prevalence and regression methods with Network Visualisations [20] for the interrelationship of dyspnoea with other symptoms and quality of life. For modelling of the ESAS dyspnoea values over days 0, 1, 3 and 7, linear mixed-effects modelling was used to compare changes in scores between groups (with and without opioids) with adjustments for age, sex, study site and baseline dyspnoea level using CRAN lme4-package [21]. A first-order autoregressive structure was fit to adjust for autocorrelation among timepoints to account for individual variation in physiological or behavioural traits on repeated measures through time [22]. The model selection process used top-down strategy recommended by Zuur *et al* [23]. All analyses were performed on RStudio 2022.02.2 software [24]. All analyses used two-sided tests, and a two-sided *p* value of 0·05 or less was considered to be statistically significant.

The research was carried out in compliance with the Helsinki Declaration, and Ethics committee approvals were obtained from the Institutional Review Boards of all the participating centres and the trial was registered with the Clinical Trials Registry – India (CTRI/2021/10/037056).

Results

Between May 1, 2019, and April 30, 2020, 5,541 patients were screened for eligibility. Two hundred and eighty-eight (35%) of 823 eligible patients were enrolled (48 patients from each of the six centres) (See Figure 1).

Screening for clinical dyspnoea as shown by the ESAS score identified the point prevalence of dyspnoea as 36.4%. Out of 288 patients who had dyspnoea, 206 (71.5%) had mild (ESAS score: 1–3), 44 (15.3%) had moderate (ESAS score: 4–6) and 38 (13.2%) had severe dyspnoea (ESAS score: >/= 7).

Clinical Study

Study participants consisted of 56.2% men, with 54.2% in the age range of 41–60 years. The most common cancers were genito-urinary in 17.9%, breast in 15%, head and neck in 13.4% and gastrointestinal in 13.1% of patients. 24.3% of patients had comorbidities, with 22% having a chronic pulmonary disease.

On ESAS, the most common symptoms were loss of well-being in 75%, tiredness in 74% and pain in 71% of patients. The quality of dyspnoea was recorded by CDS with a median value of 6.2 on the effort score, 3.8 on the anxiety score and 6.6 on the discomfort score. On the EORTC-QLQ-C-15-PAL scores for functional scales were 46.6, for symptom scales was 54.6 and for global health status was 54.4 (Table 1).

On multiple regression analysis between dyspnoea score and other items on ESAS, model validity is suggested by the p-value of the F-statistic is 1.312e-06, and significant predictor variables from the coefficients table are tiredness (t-statistic p-value = 0.04225) and loss of appetite (t-statistic p-value = 0.00475). The complexity of the interrelationships has been depicted in Figure 2 via network analysis of ESAS symptoms at baseline using force-directed plotting with Fruchterman–Reingold (normalised stress value = 0.18) (Table 2).
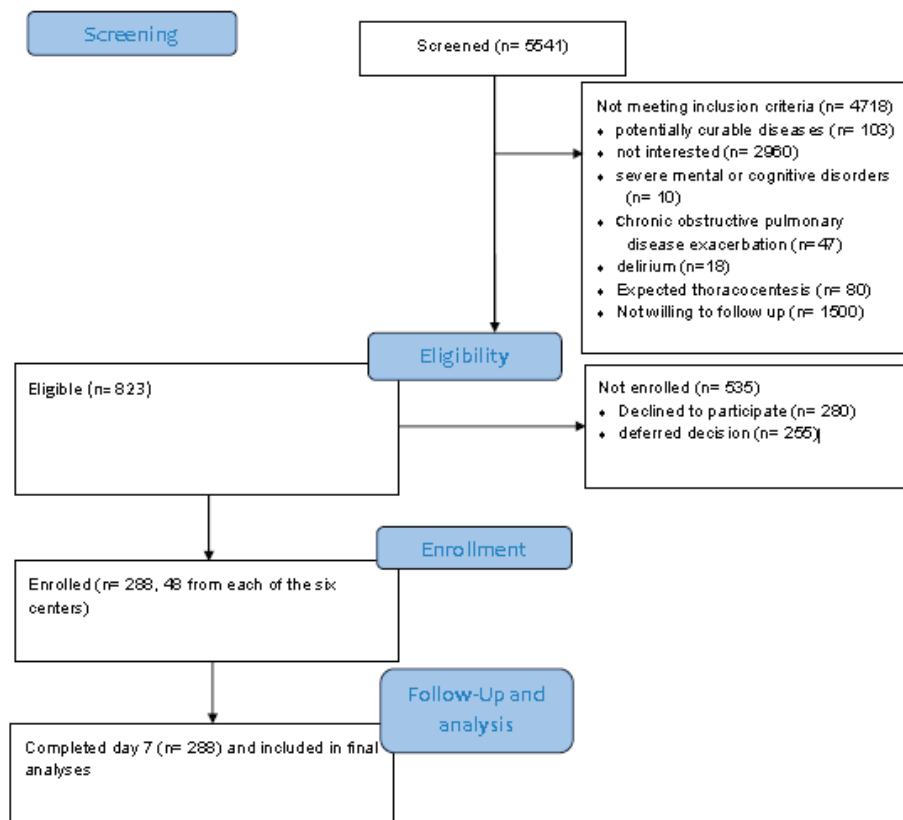
Study Flow Diagram

Figure 1. Study flow diagram.

Table 1. Demographic and clinical variables at baseline.

Variables	Description	Number (%) *n* = 288
Gender	Female Male	126 (43.75) 162 (56.25)
Age	18–40 years 41–60 years >60 years	56 (19.44) 156 (54.16) 76 (26.38)
Number of comorbidities	None 1 2 3 >4	218 (75.69) 49 (17.01) 17 (5.9) 3 (1.04) 1 (0.03)
Comorbidities (counts)	Chronic pulmonary disease	63 (22)
	Hypertension	130 (45)
	Depression	125 (43)
	Acute pulmonary disease	26 (9)
	Diabetes	9 (3)
	Chronic kidney disease	49 (17)
	Anaemia	112 (39)
Cancer type	Head and neck	39 (13.4)
	Thoracic	28 (9.6)
	Breast	43 (15)
	Hepatobiliary	18 (6.4)
	Gastrointestinal	38 (13.1)
	Genito urinary	51 (17.9)
	Sarcoma	9 (3.1)
	Skin cancers	8 (2.8)
	Central nervous system tumours	6 (1.9)
	Bone tumours	6 (2.1)
	Haematological	25 (8.6)
	Carcinoma of unknown primary	17 (6.1)
ESAS (0–10) median scores and point prevalence in %	Pain	5 (71)
	Tiredness	6 (74)
	Drowsiness	3 (16)
	Nausea	4 (31)
	Loss of appetite	4 (53)
	Shortness of breath	6 (36)
	Depression	6 (39)
	Anxiety	5 (36)
	Loss of wellbeing	5 (75)
	Others like constipation, sleep	4 (37)

Clinical Study

Table 1. Demographic and clinical variables at baseline. *(Continued)*

EORTC-QLQ-C-15-PAL scores	Functional scales	46.6
	Symptom scales	54.6
	Global health status/quality of life	54.4
CDS median score	Sense of effort	6.2
	Sense of anxiety	3.8
	Sense of discomfort	6.6
24-hour morphine consumption in milligrams (MEDD)	Day 0	24.5
	Day 1	32
	Day 3	34.5
	Day 7	35.9
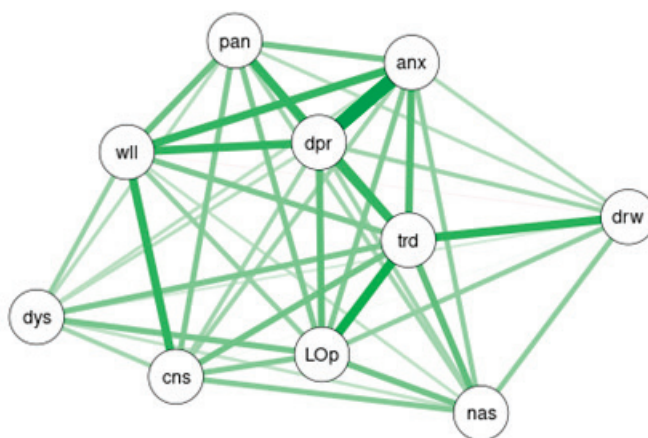
Figure 2. Network analysis of ESAS symptoms at baseline using force-directed plotting with Fruchterman–Reingold (normalised stress value = 0.18).

Of the 288 patients with dyspnoea, 112 patients received oral morphine. Of these, 90 patients received opioids for pain, and no additional opioid was given for dyspnoea. Twenty-two patients received opioids for dyspnoea. Opioid consumption per day was recorded as Morphine Equivalent Daily Dose (MEDD) for patients on days 0, 1, 3 and 7. There was an increasing trend for MEDD over 7 days (Figure 3). A Pearson product-moment correlation was run to determine the relationship between opioid usage in dyspnoea and clinical demographic parameters. There was a strong, positive correlation with total score in CDS, which was statistically significant ($r = 0.706$, $n = 22$, $p = 0.005$).

The longitudinal results for change in opioid consumption, ESAS scores for dyspnoea, CDS scores and quality of life scores were calculated in 112 (38.9%) participants with moderate-severe dyspnoea, who received opioids and could complete all four observations on days 0, 1, 3 and 7. The mean dyspnoea scores on ESAS reduced from 6.1 on day 0 to 2.8 on day 7 post opioids and standard palliative care intervention (Figure 4).

There was a reduction in effort, anxiety, discomfort and total scores of breathlessness on CDS over a follow-up period of 7 days (Figure 5).

Quality of life scores was recorded on day 0 and day 7 to identify the effect of dyspnoea management on functional scores (daily life activities), symptom scores and global health scores (overall wellbeing) of the patient. The improvement was noticed in functional scores and global health status and there was a reduction in symptom scales on day 7 on EORTC-QLQ-C15-PAL scores (Figure 6).

Table 2. Longitudinal comparison of scores day 7 versus day 0.

Test Statistics[a]									
Items	**EORTC-QLQ-C-15-PAL**			**CDS**				**ESAS Dyspnoea score**	**MEDD**
	Global health status	**Symptoms**	**Function**	**Total score**	**Sense of discomfort**	**Sense of anxiety**	**Sense of effort**		
Z	−4.953[b]	−5.454[c]	−4.728[b]	−6.738[c]	−6.642[c]	−6.227[c]	−6.336[c]	−6.041[c]	−4.234[b]
Asymp. Sig. (2-tailed)	<0.01	<0.01	<0.01	<0.01	<0.01	<0.01	<0.01	<0.01	<0.01

[a]Wilcoxon signed ranks test
[b]Based on positive ranks
[c]Based on negative ranks

Table 3. Mixed-model analysis of ESAS dyspnoea scores between the groups (with and without opioids).

	npar	**Akaike information criterion (AIC)**	**Bayesian information criterion (BIC)**	**logLik**	**Deviance**	**Chisq**	**Df**	**Pr (>Chisq)**
reduced.model (patients not using opioids)	8	3,987.1	4,003.7	−1,989.5	3,979.1			
Full.model (patients using opioids)	9	3,988.8	4,009.6	−1,989.4	3,978.8	0.2868	1	0.5923

TOTAL MORPHINE CONSUMPTION PER PATIENT (MG)

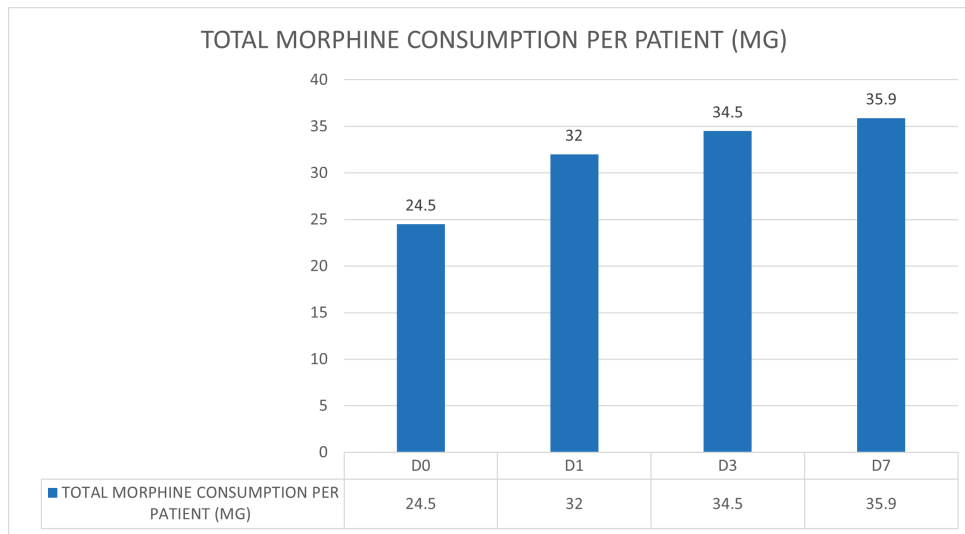|	D0	D1	D3	D7
TOTAL MORPHINE CONSUMPTION PER PATIENT (MG)	24.5	32	34.5	35.9

Figure 3. MEDD for patients on days 0, 1, 3 and 7, showing an increasing trend.

Overall, improvement in all the scores (ESAS dyspnoea scores, CDS scores, quality of life scores and MEDD) over 7 days showed a statistically significant result ($p < 0.05$). However, a mixed-model analysis showed that ESAS dyspnoea scores did not differ statistically between the groups (with and without opioids) by day 7 (Table 3).

MEAN ESAS DYSPNEA SCORES

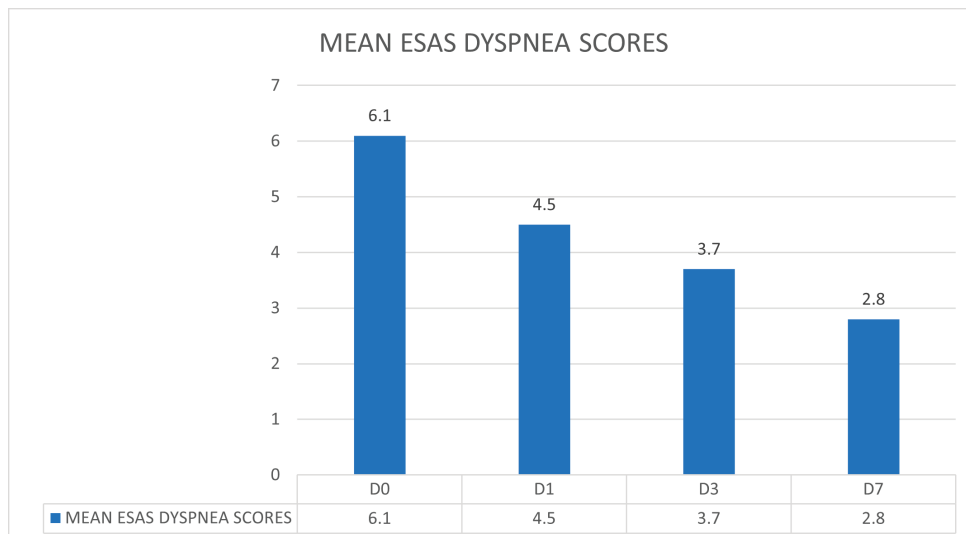|	D0	D1	D3	D7
MEAN ESAS DYSPNEA SCORES	6.1	4.5	3.7	2.8

Figure 4. The mean dyspnoea scores on ESAS showing a downward trend from 6.1 on day 0 to 2.8 on day 7 post opioids and standard palliative care intervention.

Cancer Dyspnoea Scale scores over 7 days

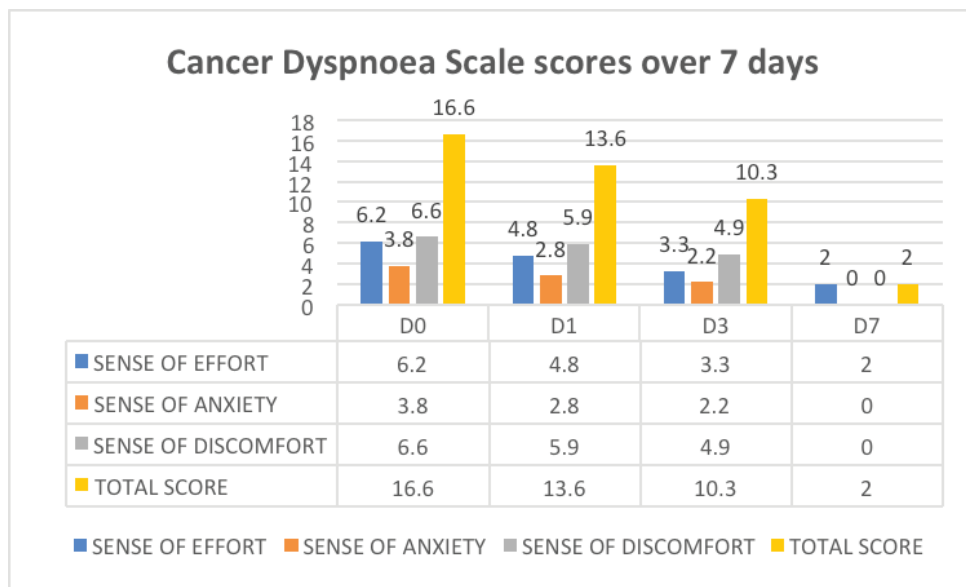|	D0	D1	D3	D7
SENSE OF EFFORT	6.2	4.8	3.3	2
SENSE OF ANXIETY	3.8	2.8	2.2	0
SENSE OF DISCOMFORT	6.6	5.9	4.9	0
TOTAL SCORE	16.6	13.6	10.3	2

Figure 5. CDS scores in effort, anxiety, discomfort and total scores of breathlessness over 7 days.

A correlation between ESAS scores of dyspnoea and the feeling of well-being after the use of morphine (*n* = 22) (where 10 signifies Worst Possible Wellbeing) suggests a positive Pearson correlation coefficient of 0.83, *p* value of <0.001.

EORTC-QLQ-C15-Pal scores over 7 days

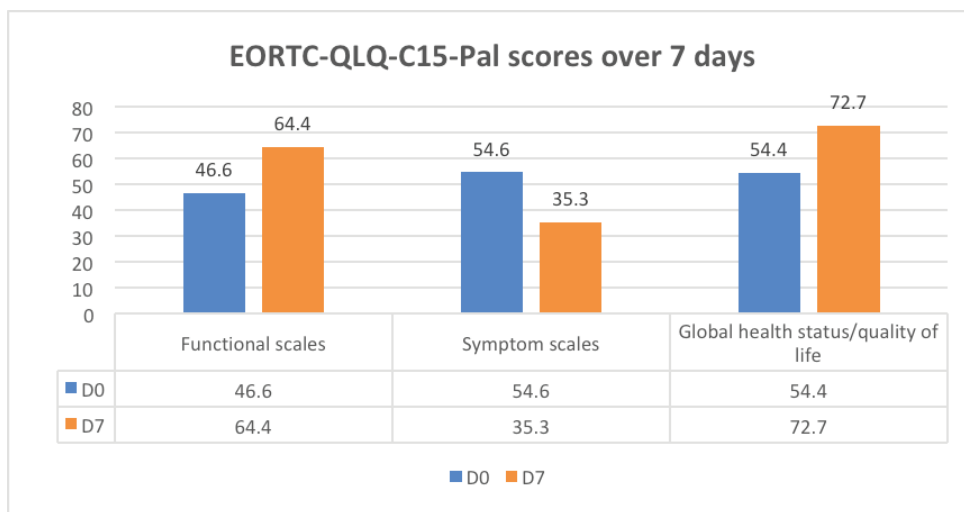|	Functional scales	Symptom scales	Global health status/quality of life
D0	46.6	54.6	54.4
D7	64.4	35.3	72.7

Figure 6. EORTC-QLQ-C15-PAL scores on day 0 and day 7, showing improvement in functional scores and global health status and a reduction in symptom scales.
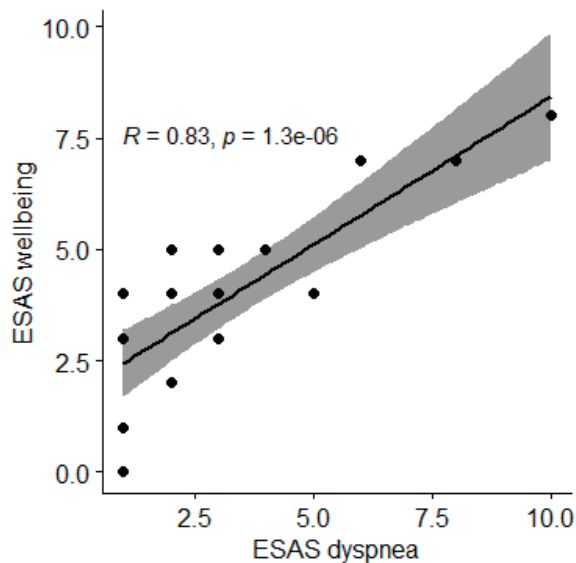

$R = 0.83$, $p = 1.3e\text{-}06$

Figure 7. Correlation between ESAS scores of dyspnoea and the feeling of well-being after the use of morphine (*n* = 22).

Discussion

This is the first study determining the prevalence of breathlessness among palliative care outpatient clinic patients in major cancer centres in India from different parts of the country [25]. As many as 36.4% of patients attending the clinics present with breathlessness and one-quarter of them report severe breathlessness. It was heavily related to other symptoms, and thus was one of the most important symptoms in study participants.

Large-scale measurement of dyspnoea in clinics is feasible. Across all the participating centres, study investigators suggested that subjective assessment of dyspnoea and correct documentation was an important part of the patient-centred care approach. They also noticed that the process was less time-consuming, and that the unidimensional dyspnoea assessment measures using the 0–10 Likert scale were efficient for screening dyspnoea in busy outpatient settings. However, multidimensional assessments are preferred in specialised palliative care practice, which is essential for a better understanding of the factors contributing to the patient's overall symptom experience [26]. The study results of this study were based upon the data obtained from the patients directly attending palliative medicine outpatient clinics over 1 year. In a study by Baker *et al* [27], the authors described similar findings and suggested that palliative care nurses can use unidimensional and multi-dimensional measures to assess and characterise breathlessness in busy clinical settings.

In this study, data collection and symptom assessment were done while the patients were seated for a while after arrival at the clinic. Hence, logically these ratings suggest dyspnoea in the non-exertional and resting condition of the patient. It was noticed that patients with cardio-respiratory system involvement due to cancer or other co-morbidities like chronic obstructive pulmonary disease, heart diseases and chronic kidney disease reported higher intensity of dyspnoea, with a score > 4/10. Also, those patients who reported pain score > 4/10 (n = 123), and fatigue score > 4/10 (n = 101) at the time of assessment had a 2.8- and 2.3-times higher prevalence of dyspnoea, respectively. These patients also reported higher intensity of dyspnoea. This depicts the impact of comorbidities and the presence of other symptoms on the patient's overall experience of dyspnoea.

ESAS estimates the level of dyspnoea to examine the average symptom intensity over the past 24 hours. This recalled dyspnoea rating is subjective, as it varies depending on the amount of physical exertion and overall experience during the interval time, and physiologically represents cardiorespiratory demand about delivery [28]. Most patients reported that their experience of the worst dyspnoea was not related to the level of exertion. This should not be surprising, as the study sample comprised of cases with advanced cancers with a conglomeration of other symptoms related to dyspnoea.

The reported prevalence of dyspnoea in advanced cancer patients is 36.4% in this study, which is comparable to a meta-analysis that included more than 10,000 patients with advanced cancer, with 10%–70% of patients reporting dyspnoea [2]. This difference can be due to the difference in the assessment of dyspnoea. Most studies in the literature assessing the prevalence of dyspnoea have used the Medical Research Council (MRC) dyspnoea scale [29]. The MRC identifies the level of breathlessness based on the level of exertion that provokes breathlessness and is a more objective measure. We used more subjective assessment tools, to determine the overall perception of dyspnoea.

The American Society of Clinical Oncology in their 2021 guideline for management of dyspnoea in advanced cancer recommended the usage of systemic opioids for patients who derive inadequate relief from nonpharmacologic interventions [30]. In a dose-finding pilot double-blind randomised clinical trial by Hui *et al* [31] prophylactic fentanyl improved breathlessness and walk distance (pre–post analysis) compared with placebo. Our study design unfortunately does not allow us to claim that opioid usage led to alleviation of dyspnoea using a mixed-model analysis; however, we documented that the usage of opioids preceded dyspnoea alleviation here. This is significant for Indian settings, as apart from the fear of respiratory depression and accelerated death with the usage of opioids [32], there are barriers to opioid usage/availability like bureaucratic hurdles and sociocultural/infrastructure challenges[33].

Our study data are restricted to palliative care outpatient clinics, and thus do not include many patients who attend oncology clinics. In high-risk groups with cardiac and pulmonary comorbidities, literature reports an increased prevalence of dyspnoea, up to 50%–70% [34]. We noticed differences in the prevalence of dyspnoea based on patient demographics like gender and age. Both patient and clinician gender

Clinical Study

influence the expectation of dyspnoea and its treatment [35]. These findings were consistent with the findings of Santos *et al* [36], who reported a higher prevalence of breathlessness among female gender and elderly patients.

We used clinic data for research purposes with necessary approval, which is considered real-life data and superior to administrative data. All patients provided a numerical rating for ESAS symptoms including dyspnoea. Such ordinal scoring captures full information, rather than a binary yes/no. For binary response choices, a participant may need some specific intensity of breathlessness to respond 'yes' to the presence of sensation and this magnitude may vary from person to person in different situations [37]. Our analyses cannot account for biases related to reporting, perceived experience or documentation.

ESAS data were collected by research staff including trained nurses and doctors. The data represents the real-world scenario and can be related to practical experiences in outpatient clinics:

1) Dyspnoea, being a subjective experience, should be patient-reported. However, doctors and nurses use some objective measures for respiratory distress to supplement patients' reporting of breathlessness. One of the reasons for this is perceived difficulty for patients to quantify the experience of breathlessness in a numeric scale or in cases where patient is unable to vocalise. Hence, it is worthwhile to use some objective measures of 'observed respiratory distress' in addition to the subjective reporting, to have more robust information.

For all the study participants who complete the reporting, we acknowledge that 10%–15% of participants may find it difficult to translate their perceived symptom experience to a numeric value. Ideally, such patients are 'poor raters' and should be excluded from the actual data analysis. We acknowledge the error in measurement that might have crept in due to their presence in the study population. The study investigators across all participating centres agreed with the fact that these 'poor raters' were the patients who are unable to numerically rate all the subjective experiences like pain, breathlessness and other symptoms. This is noteworthy while assessing the patients in routine clinical practice, to be aware of false reporting.

2) Ideally, dyspnoea assessment should be done at the first visit to the hospital, but such assessments are challenging and were out of scope of this study. The prevalence of dyspnoea as indicated in this study may not be the true representation of patients presenting to hospital with breathlessness. It might have been slightly under-estimated as some of the severely breathless patients, who are unstable at presentation, will be shifted to the emergency department upon arrival, to receive treatment before the study enrolment could be made. To help circumvent this coverage gap, both ESAS and CDS include an item for assessment of dyspnoea in past few days before presentation to hospital, recall for dyspnoea experience in this period is dependable.

Conclusion

Dyspnoea is one of the most distressing symptoms in patients with cancer. In this study, a third of the patients presented with dyspnoea of moderate to severe intensity. Cancer-associated dyspnoea includes multiple causes ranging from cancer itself to multiple ongoing comorbidities, respiratory and cardiovascular causes being the major ones. Although dyspnoea is less prevalent than pain, it should be routinely assessed as it significantly adds to both physical and emotional suffering. It is evident that assessment and documentation of dyspnoea are easy, less time-consuming and can be accurately done by all healthcare professionals, including doctors and nurses and its management significantly impacts overall patient experiences. The usage of opioids preceded dyspnoea alleviation in this study. We recommend that dyspnoea assessment should be routinely included as a part of the patient care plan, and opioids should be opted for palliation of dyspnoea.

Disclosures and conflicts of interest

The authors have no conflicts of interest to disclose. De-identified individual participant data underlying the results reported in this paper will be available, for 5 years after publication, to investigators for uses approved by the institutional review board of the Tata Memorial Hospital. Proposals should be directed to the corresponding author. Acceptance of a data access agreement will be required for access.

Clinical Study

Author contributions statement

AG, AD, MAM and JD contributed to the conception or design of the work; AG, AD, PS, SM, VV, AGr, PSa and SB helped in data collection; AG and AD contributed to data analysis, interpretation and drafting the article; AG, AD, MAM, PS, JD, SM, VV, AGr, PSa, SB helped in critical revision and drafting the final version of the article to be published.

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Clinical Study

Appendices

Appendix I

Dyspnea Visual Analogue Scale (VAS-D)

It is a 10 cm uncalibrated horizontal line and has been translated and validated in Hindi and Marathi. The left end of the line is labeled "I Can Breathe as I Normally Do" and the right end of the line is labeled "I Can't Breathe at all". The patient's mark was then converted to a score by measuring the distance from the left end of the line to the nearest 1 mm. Therefore, a dyspnea VAS score of 0 corresponds to the patient's subjective feeling of "I Can Breathe Normally" and a dyspnea VAS score of 100 corresponds to "I Can't Breathe at all."

Dyspnea Visual Analogue Scale (VAS-D)- VAS-D (English)

VAS-D (Hindi)

VAS-D (Marathi)

व्हीजुवल ॲनालॉंग स्केल

तुम्हाला या क्षणी किती श्वासकष्ट आहे ? कृपया खाली दिलेल्या रेषेवर खूण करून दाखवा. तुम्हाला काहीच श्वासकष्ट नसल्यास, रेषेच्या डाव्या टोकेवर खूण करावी.

काहीच श्वासकष्ट नाही   सर्वात जास्त श्वासकष्ट

0   90
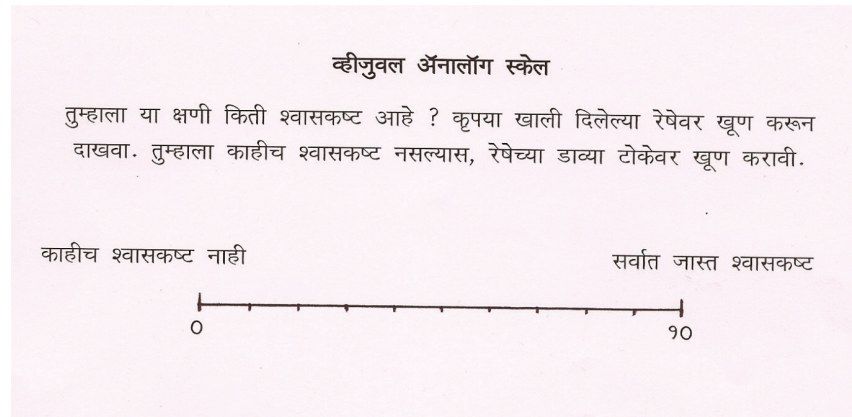
Appendix II

Cancer Dyspnea Scale (CDS)

The CDS is a 12-item self-rating scale validated to evaluate the multidimensional nature of dyspnea in cancer patients and has been translated and validated in Hindi and Marathi. The CDS consists of three factors: 1) "sense of effort" (5 items), 2) "sense of anxiety" (4 items), and 3) "sense of discomfort" (3 items). Each item is rated on a 5-point scale. The maximum score is 48 points. The higher the score, the more severe is the patient's dyspnea.

CDS-English

The Cancer Dyspnoea Scale

We would like to ask you about your breathlessness or difficulty in breathing. Please answer each question by circling only the numbers that best describes the breathing difficulty that you felt *during the past few days*. Base your response on your first impression.

	Not at all	A little	Somewhat	Considerably	Very much
1 Can you inhale easily?	1	2	3	4	5
2 Can you exhale easily?	1	2	3	4	5
3 Can you breathe slowly?	1	2	3	4	5
4 Do you feel short of breath?	1	2	3	4	5
5 Do you feel breathing difficulty accompanied by palpitations and sweating?	1	2	3	4	5
6 Do you feel as if you are panting?	1	2	3	4	5
7 Do you feel such breathing difficulty that you don't know what to do about it?	1	2	3	4	5
8 Do you feel your breath is shallow?	1	2	3	4	5
9 Do you feel your breathing may stop?	1	2	3	4	5
10 Do you feel your airway has become narrower?	1	2	3	4	5
11 Do you feel as if you are drowning?	1	2	3	4	5
12 Do you feel as if something is stuck in your airway?	1	2	3	4	5

CDS-Hindi

हम आपके श्वासकष्ट अथवा सांस लेने में कठिनाई के बारे में पूछताछ करना चाहते है । कृपया हर सवाल का जवाब इसके आगे दिए गए केवल उस अंक पर गोल बनाकर दे, जो पिछले कुछ दिनों में आपकी श्वास की कठिनाई का स्वरूप बताता है । आपका जवाब आपके प्रथन विचारपर आधारित करें।

		बिलकुल नही	थोडसा	थोडा अधिक	काफी	बहुत अधिक
१)	क्या आप आसानी से सांस अंदर लं सकतें हो ?	१	२	३	४	५
२)	क्या आप आसानी सें सांस छोड़ सकतें हो ?	१	२	३	४	५
३)	क्या आप धीरे सें सांस ले सकते हो ?	१	२	३	४	५
४)	क्या आप सांस की कमी महसूस करते हो ?	१	२	३	४	५
५)	क्या आपको सांस की तकलिफ के साथ धकधकी महसूस होती है, और पसिना आता है ?	१	२	३	४	५
६)	क्या आपका दम फूलता है ?	१	२	३	४	५
७)	क्या आप सांस लेने में इतकी कठिनाई महसूस करते हो की आपको सुझता नही की उसके बारे में क्या करे?	१	२	३	४	५
८)	क्या आप अपनी सांस में उथलापन महसूस करते हो ?	१	२	३	४	५
९)	क्या आपको महसूस होता हैं की शायद आपकी सांस रुक जाएगी ?	१	२	३	४	५
१०)	क्या आपको महसूस होता है की आपका श्वासमार्ग संकुचित हो गया है ?	१	२	३	४	५
११)	क्या आपको ऐसा महसूस होता है की आप डूब रहें हो ?	१	२	३	४	५
१२)	क्या आपको ऐसा महसूस होता है की आपके श्वासमार्ग में कुछ अटक गया है ?	१	२	३	४	५

CDS-Marathi

आम्ही तुम्हाला तुमच्या श्वासोच्छवासाच्या तक्रारीबद्दल विचारु इच्छितो. कृपया प्रत्येक प्रश्नाचे उत्तर, त्या समोर दिलेल्या फक्त त्या आकड्याभोवती वर्तुळ करुन द्यावे. जे तुम्ही गेल्या काही दिवसात अनुभवत असलेल्या तुमच्या श्वासाच्या तक्रारीचे स्वरुप दर्शवतो. तुमचा प्रतिसाद तुमच्या प्रथम दर्शनी अनुभवावर अवलंबून राहील.

		अजिबात नाही	किंचित	थोड जास्त	बराच	खूपच
१)	तुम्ही सहजपणे श्वास घेऊ शकता का ?	१	२	३	४	५
२)	तुम्ही सहजपणे श्वास सोडू शकता का ?	१	२	३	४	५
३)	तुम्ही संथपणे श्वास घेऊ शकता का?	१	२	३	४	५
४)	तुम्हाला दम लागतो का ?	१	२	३	४	५
५)	तुम्हाला श्वासकष्टाबरोबर हृदयाची धडधड व घाम जाणवतो का?	१	२	३	४	५
६)	तुम्हाला धाप लागते का ?	१	२	३	४	५
७)	तुम्हाला श्वासोच्छवासाच्या अशा अडचणी जाणवतात का, कि ज्यामुळे तुम्हाला काय करावे हे सूचत नाही?	१	२	३	४	५
८)	तुम्हाला तुमचा श्वास उथळ वाटतो का?	१	२	३	४	५
९)	तुमचा श्वास कदाचित थांबेल असे तुम्हाला वाटते का ?	१	२	३	४	५
१०)	तुमचा श्वासमार्ग संकुचित झाला आहे असे तुम्हाला वाटते का?	१	२	३	४	५
११)	तुम्हाला बुडल्यासारखे वाटते का?	१	२	३	४	५
१२)	तुम्हाला तुमच्या श्वासमार्गात काही अडथळा जाणवतो का?	१	२	३	४	५

Calculation method

1. Add the scores for each factor together.
   Factor 1 = (items 4 + 6 + 8 + 10 + 12) − 5   = sense of effort
   Factor 2 = (items 5 + 7 + 9 + 11) − 4   = sense of anxiety
   Factor 3 = 15 − (items 1 + 2 + 3)   = sense of discomfort
2. Add the total scores for each factor together   = total dyspnoea

*Subtractions are to make adjustments for 0 as a state of absence of dyspnoea.

Appendix III

European Organization for Research and Treatment of Cancer Quality of Life Core 15 Palliative (EORTC QLQ-C15 PAL)

EORTC C-15 PAL is a tool developed to measure the quality of life in cancer patients in a palliative care setting and has been translated and validated in Hindi and Marathi. It consists of 15 questions, which are transformed into two function scales ('Physical Functioning', 'Emotional Functioning'), seven symptom scales ('Fatigue', 'Nausea/Vomiting', 'Pain', 'Dyspnea', 'Insomnia', 'Appetite loss', 'Constipation') and an 'Overall quality of life' scale. Patients should answer the questions according to their experiences during the previous week. Responses to 14 questions are given on a four-point Likert scale with 1 'Not at all', 2 'A little', 3 'Quite a bit', and 4 'Very much', the question to overall QoL allows answers between 1 'Very poor' and 7 'Excellent'.

HINDI

EORTC QLQ-C15-PAL (version 1)

हम आपके और आपके स्वास्थ्य के बारे में कुछ वातें जानना चाहते हैं । कृपया आप सव पश्नों का उत्तर स्वंय उस अंक पर गोला वनाकर दें जो आपको सबसे सही लगता है । कोई भी उत्तर सही या गलत नहीं है । आपके द्वारा दी गयी जानकारी गुप्त रखी जाएगी ।

आपके नाम के अक्षर :
आपकी जन्मतिथि (दिन, मास, वर्ष) :
आज की तिथि (दिन, मास, वर्ष) :

		बिलकुल नहीं	थोड़ा सा	थोड़ा अधिक	बहुत अधिक
1.	क्या आपको घर के आसपास थोड़ा टहलने में कोई तकलीफ होती है?	1	2	3	4
2.	क्या आपको दिन में कुर्सी में वैठने की या विस्तर पर लेटे रहने की जरूरत महसूस होती है?	1	2	3	4
3.	क्या आपको खाने, कपड़े पहनने, नहाने या शौचालय जाने में मदद की जरूरत पड़ती है?	1	2	3	4

पिछले एक सप्ताह के दौरान:

		बिलकुल नहीं	थोड़ा सा	थोड़ा अधिक	बहुत अधिक
4.	क्या आपको सौंस लेने में तकलीफ हुई?	1	2	3	4
5.	क्या आपको दर्द था?	1	2	3	4
6.	क्या आपको सोने में कठिनाई हुई?	1	2	3	4
7.	क्या आपको कमजोरी महसूस हुई?	1	2	3	4
8.	क्या आपकी भूख कम हो गयी थी?	1	2	3	4
9.	क्या आपको मचली महसूस होती थी?	1	2	3	4

Clinical Study

पिछले एक सप्ताह के दौरान		बिलकुल नहीं	थोड़ा सा	थोड़ा अधिक	बहुत अधिक
10.	क्या आपको कब्जियत रही थी?	1	2	3	4
11.	क्या आपको थकान महसूस होती थी?	1	2	3	4
12.	क्या दर्द के कारण आपके दैनिक कार्यों में रूकावट आयी?	1	2	3	4
13.	क्या आप तनाव महसूस करते थे?	1	2	3	4
14.	क्या आप उदास रहे?	1	2	3	4

इन प्रश्नों का उत्तर 1 से 7 तक के अंको में से उस पर गोला बनाकर दें, जो आप पर सबसे ज्यादा लागू होता हो .

15. पिछले सप्ताह के अपने कुल जीवन स्तर का मूल्यांकन आप कैसे करेंगे?

1	2	3	4	5	6	7
बहुत ख़राब						बहुत अच्छा

EORTC QLQ-C15-PAL (version 1)

आपली व आपल्या आरोग्याविषयाची माहिती जाणून घेण्यास आम्ही उत्सुक आहोत . कृपया आपल्याला लागू पडणारी सर्व उत्तरे आपण स्वतः योग्य त्या आकडयाभोवती वर्तुळ करून द्यावीत . ही उत्तरे बरोबर अथवा चूक या सदरात मोडत नाहीत . आपण पुरवलेली माहीती अतिशय गुप्त राखली जाईल .

आपल्या नावाची अद्याक्षरेः

जन्मतारीखः (दिवस, महिना, वर्ष)ः

आजची तारीखः (दिवस, महिना, वर्ष)ः

		अजिबात नाही	थोडा	बराच	खूपच
१.	आपणास जास्त लांब चालल्यावर काही त्रास होतो का?	१	२	३	४
२.	आपणास दिवसभरात गुर्चीत बसून अथवा पलंगावर पडून राहण्याची गरज भासते का?	१	२	३	४
३.	आपणास जेवताना, कपडे घालताना, स्नान करताना अथवा शौचादी कामासाठी मदत घ्यावी लागते का?	१	२	३	४

गेल्या आठवडयात:		अजिबात नाही	थोडा	बराच	खूपच
४.	आपणास धाप लागली होती का?	१	२	३	४
५.	आपणास वेदना झाल्या होत्या का?	१	२	३	४
६.	आपणास झोपेचा काही त्रास झाला होता का?	१	२	३	४
७.	आपणास अशक्तपणा वाटला होता का?	१	२	३	४
८.	आपली भूक मंदावली होती का?	१	२	३	४
९.	आपणास मळमळल्यासारखे वाटले होते का?	१	२	३	४

कृपया पुढील पानावर जा

गेल्या आठवड्यात:	अजिबात नाही	थोडा	बराच	खुपच
१०. आपणास वध्दकोष्टतेचा त्रास झाला का?	१	२	३	४
११. आपणास थकवा जाणवला का?	१	२	३	४
१२. वेदनेमुळे आपल्या दैनीक व्यवहारात अडथळा आला का?	१	२	३	४
१३. आपणास मानसिक ताण जाणवला का?	१	२	३	४
१४. आपण उदास होता का?	१	२	३	४

खालील प्रश्नांची उत्तरे १ ते ७ मधील आपल्याला लागू पडणा-या आकड्याभोवती वर्तुळ करून धावीत.

१५. मागील आठवड्यातील आपल्या <u>जीवनाच्या दर्जाचे मूल्यमापन</u> आपण कसे कराल?

१	२	३	४	५	६	७
अति वाईट.						उत्कृष्ट.