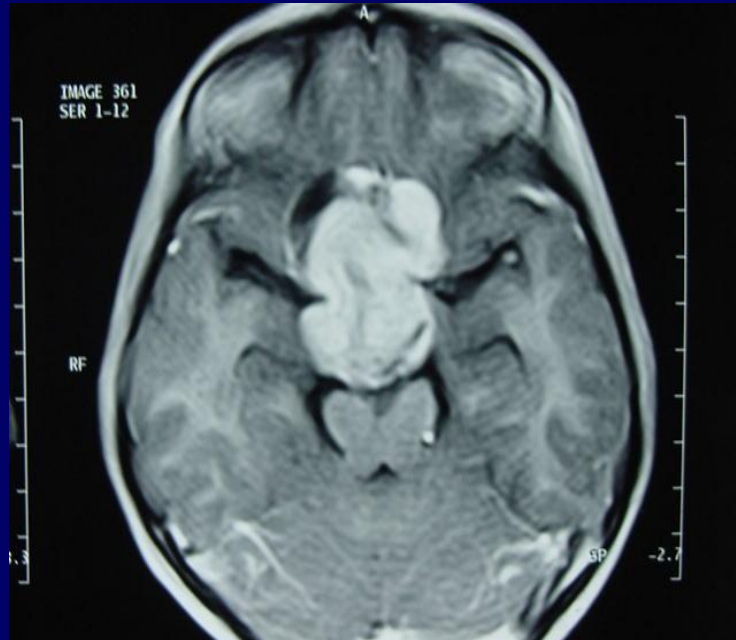
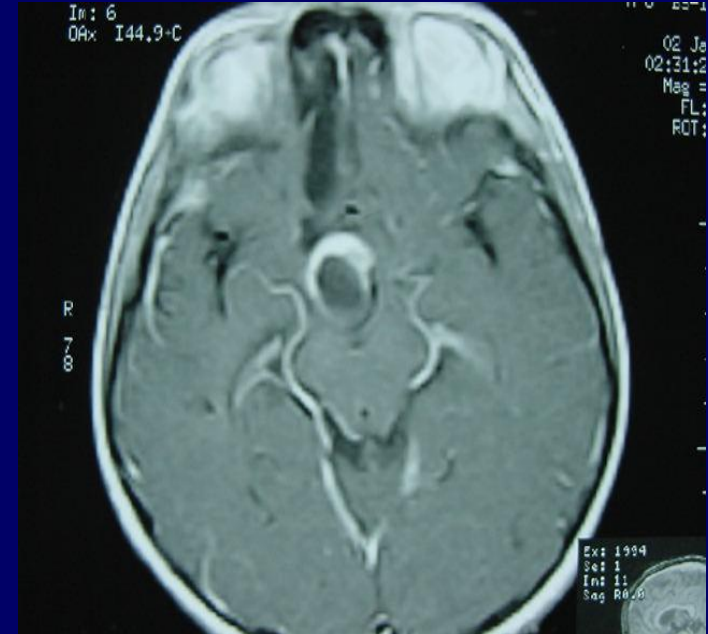


Pre treatment



Post treatment



- Health related QOL – individual's perception of well being
- Important endpoint in high grade and low grade tumours
- Includes physical, mental, emotional and social domains



Quality of life- an important outcome measure

Most of the data on QoL is available in trial setting

Disease

versus

Illness

Observed by physician

Objective signs

Replicable

Affects discrete parts

Affects quantity of life

Dispassionate care

Death (survival)

Experienced by patient

Subjective symptoms

Unique

Affects whole person

Affects quality of life

Compassionate care

Suffering

Shift of focus

- The person with **CANCER**


Vs

- The **PERSON** with cancer

- *A small difference with a big effect*

QOL Tools in brain tumours

ENGLISH



EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials: _____
 Your birthdate (Day, Month, Year): _____
 Today's date (Day, Month, Year): 31 _____

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4

Please go on to the next page

Core questionnaire (30 qtns)



EORTC QLQ - BN20

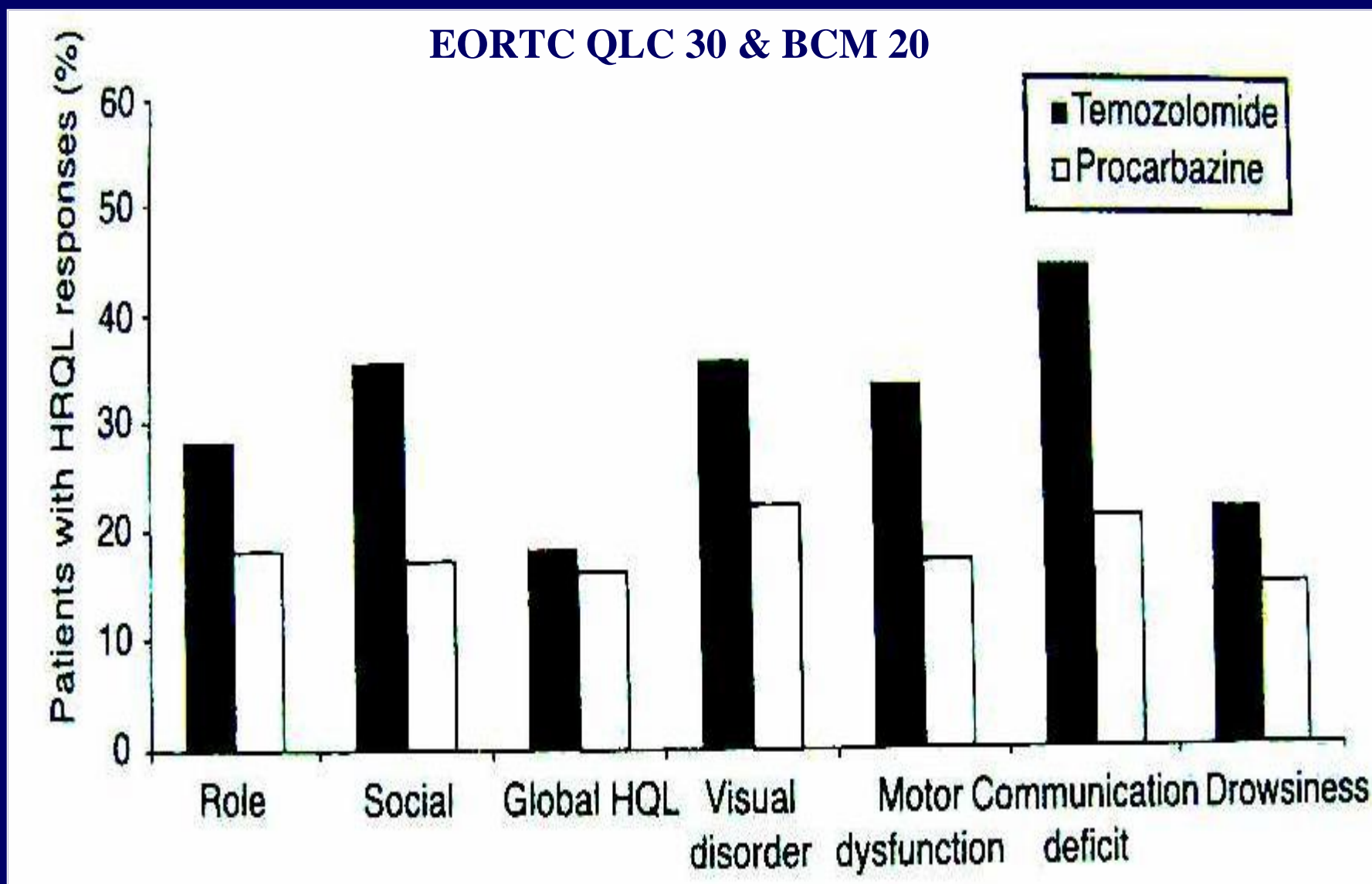
Patients sometimes report that they have the following symptoms. Please indicate the extent to which you have experienced these symptoms or problems during the past week.

	Not at All	A Little	Quite a Bit	Very Much
31. Did you feel uncertain about the future?	1	2	3	4
32. Did you feel you had setbacks in your condition?	1	2	3	4
33. Were you concerned about disruption of family life?	1	2	3	4
34. Did you have headaches?	1	2	3	4
35. Did your outlook on the future worsen?	1	2	3	4
36. Did you have double vision?	1	2	3	4
37. Was your vision blurred?	1	2	3	4
38. Did you have difficulty reading because of your vision?	1	2	3	4
39. Did you have seizures?	1	2	3	4
40. Did you have weakness on one side of your body?	1	2	3	4
41. Did you have trouble finding the right words to express yourself?	1	2	3	4
42. Did you have difficulty speaking?	1	2	3	4
43. Did you have trouble communicating your thoughts?	1	2	3	4
44. Did you feel drowsy during the daytime?	1	2	3	4
45. Did you have trouble with your coordination?	1	2	3	4
46. Did hair loss bother you?	1	2	3	4
47. Did itching of your skin bother you?	1	2	3	4
48. Did you have weakness of both legs?	1	2	3	4
49. Did you feel unsteady on your feet?	1	2	3	4
50. Did you have trouble controlling your bladder?	1	2	3	4

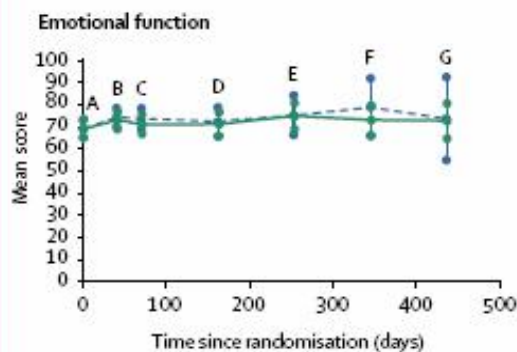
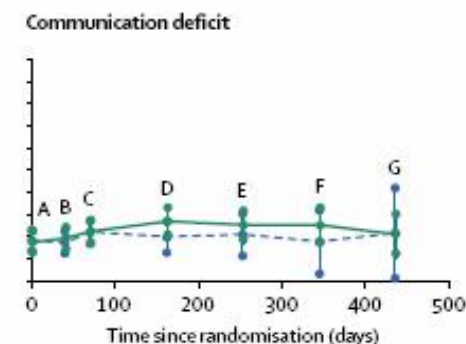
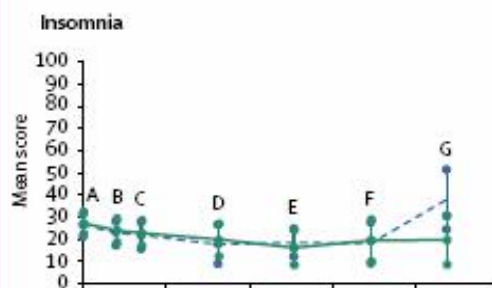
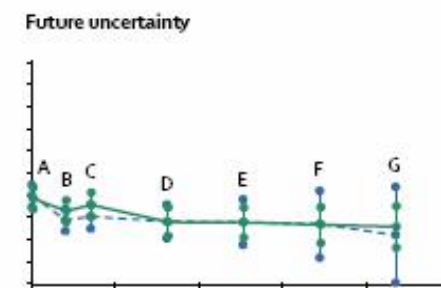
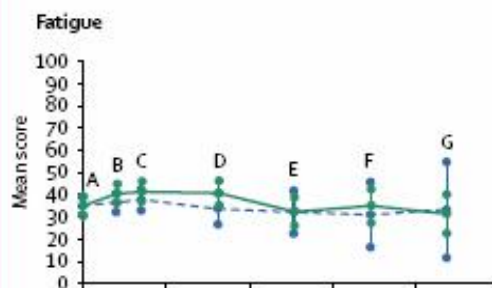
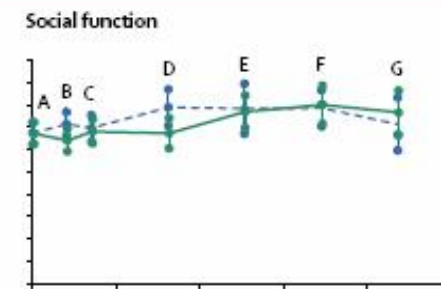
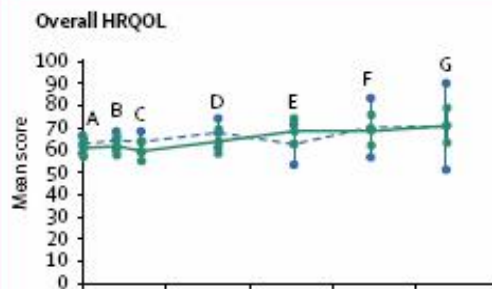
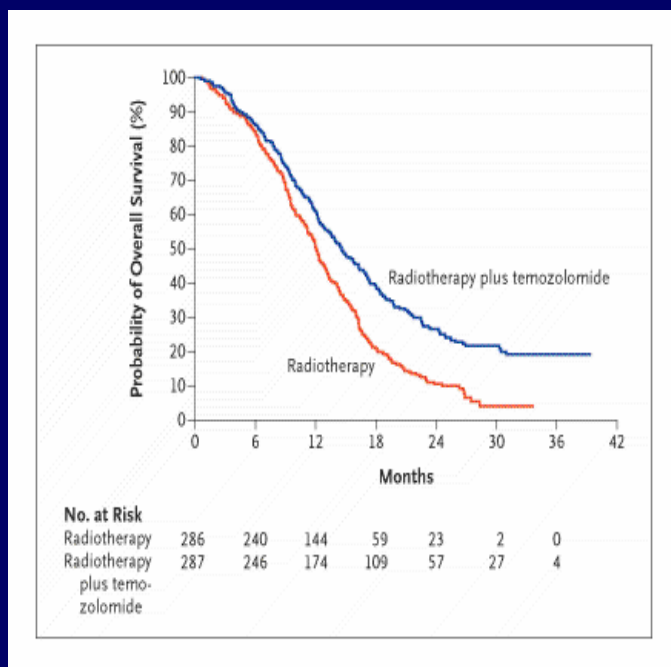
© Copyright 1994 EORTC Study Group on Quality of Life. (phase III module)

Specific brain module (20 qtns)

Quality of Life in recurrent gliomas



Prospective QOL assessment in the EORTC TMZ study



— Radiotherapy and temozolomide
- - - Radiotherapy



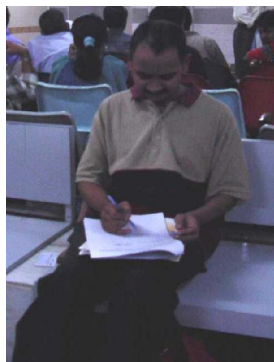
Problems of QOL in routine practice

- Social and cultural factors
- Indifference of treating physician towards QOL issues
- Non availability of QOL tools in native languages
- Longitudinal prospective studies on late sequelae and QOL sparse
- Most of the data retrospective/cross-sectional
- QOL in routine practice relatively unknown and difficult to do



TMH QOL study in adult Brain tumour patients

- Longitudinal
- Consecutive



Study Design



- **Accrual**

Adult patients (age > 18 years) with primary brain tumours seen consecutively from 1st Jan 2003 to 31st December 2003
(all patients had some surgical intervention)

- **Prospective Evaluation**

Complete neuro-oncological data

EORTC Questionnaire-QLQ C30 (QOL)

EORTC approved translated Brain Cancer Module (BN 20)

(Hindi and Marathi)

Translation to Hindi and Marathi and Validation

- Detailed methodology, as outlined by EORTC
- First, forward translations by 2 native speakers
- Intermediate questionnaire
- Back translations by 2 independent people
- Application in 10 patients and evaluate their responses as a pilot testing
- Send to EORTC & incorporate the changes suggested
- Submit final questionnaire to EORTC for acceptance and ratification
- Available at the EORTC website, copyrighted

Table 2: EORTC QLQ- Translated Final Hindi Questionnaire

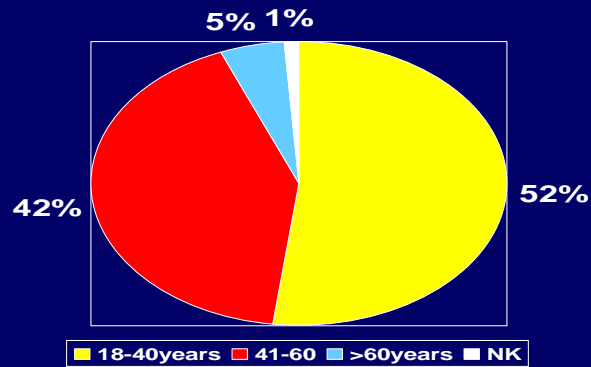
EORTC QLQ - BN20

मरीज कुछ बार नीचे लिखे हुई तकलीफें बताते हैं कृपया आप हमें बताएं कि आपको पिछले मन्ताह में किस हद तक तकलीफ हुई

क्र . पिछले एक मन्ताह / हप्ते में	बिलकुल नहीं	थोडासा	जादा	बहुत जादा
१ . क्या आपको अपना भविष्य अनिश्चित लगा ?	१	२	३	४
२ . क्या आपको लगा की आपकी स्थितियों में कुछ रुकावटें आयी ?	१	२	३	४
३ . क्या आपको अपने परिवारिक जीवन के टुटनेकी चिन्ता हुई ?	१	२	३	४
४ . क्या आपको सिरदर्द था ?	१	२	३	४
५ . क्या आपका भविष्य के बारे में नजरिया बिगडा ?	१	२	३	४
६ . क्या आपको कोई वस्तु दो (दुगुनी) दिखती थी ?	१	२	३	४
७ . क्या आपको धुंधला दिखता था ?	१	२	३	४
८ . क्या आपको नजर की वजहसे पढ़ने में कोई दिक्कत हुई ?	१	२	३	४
९ . क्या आपको कोई मिरगी / झटका आया ?	१	२	३	४
१० . क्या आपको शरीर के एक तरफ के भाग में कोई कमजोरी थी ?	१	२	३	४
११ . क्या आपको अपने विचार पगट करने में उपयुक्त शब्द छुंढने में कठिनाई होती थी ?	१	२	३	४
१२ . क्या आपको बोलते समय तकलीफ होती थी ?	१	२	३	४
१३ . क्या आपको विचारों के लेन देन में कठिनाई होती थी ?	१	२	३	४
१४ . क्या आपको दिन में सोने जैसे लगता था ?	१	२	३	४
१५ . क्या आपके तालमेल में कठिनाई आयी ?	१	२	३	४
१६ . क्या आप बाल झडने से परेशान होते थे ?	१	२	३	४
१७ . क्या खचा की खुजली ने आपको परेशान किया ?	१	२	३	४
१८ . क्या आपको दोनो टांगो में कमजोरी थी ?	१	२	३	४
१९ . क्या आपको पैरो में असंतुलन महसूस होता था ?	१	२	३	४
२० . क्या आपको पेशाब नियंत्रण करने में तकलीफ होती थी ?	१	२	३	४

Patient characteristics

Total no of patients accrued: 257



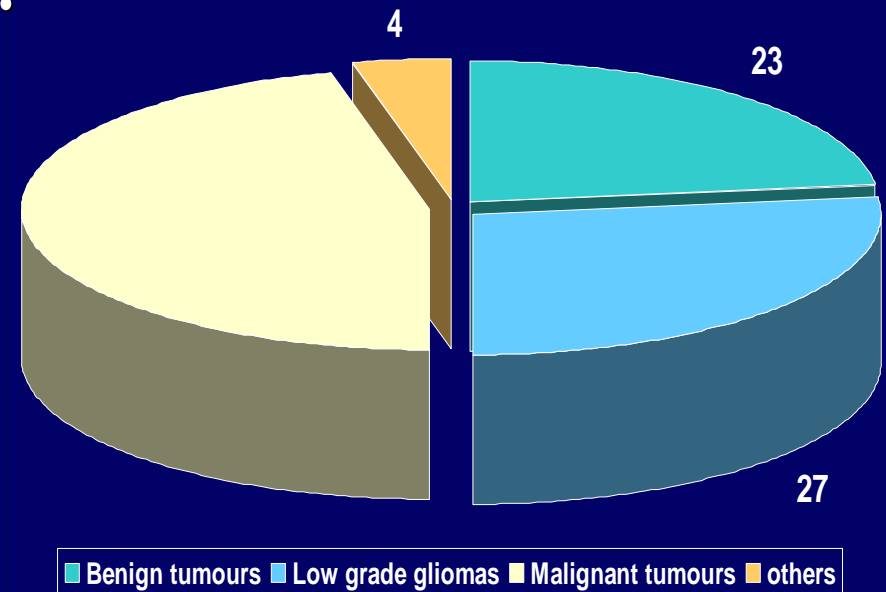
• KPS

80 and above: 183 (71%)
 50-70: 57 (22%)
 <40: 10 (4%)

■ **Male : Female** :: 173 : 84

■ Literacy status:

Illiterate: 36 (14%)
 Primary education: 31 (12%)
 Secondary education: 91 (35%)
 Higher sec. education: 48 (19%)
 College and above: 46 (18%)
 Not available: 5 (2%)



Evaluations

- Questionnaire filled by patients themselves: 165 (64%)
- Assistance required due to neurological condition: 37 (14.5%)
- Assistance required due to illiteracy: 33 (13%)
- Assistance required for other causes: 20 (8%)

Time of evaluation

Visit 1:	At first assessed in the Clinic (n=243)
Visit 2:	At the conclusion of Radiation therapy (n=147)
Visit 3:	On follow up at 6 weeks to 3 months (n=114)
Visit 4:	On follow up at 6 months (n=62)
Visit 5:	On follow up at 9-12 months (n=50)

	No.
Died	21
Lost	14
No RT/Out RT	30
Administrative	31

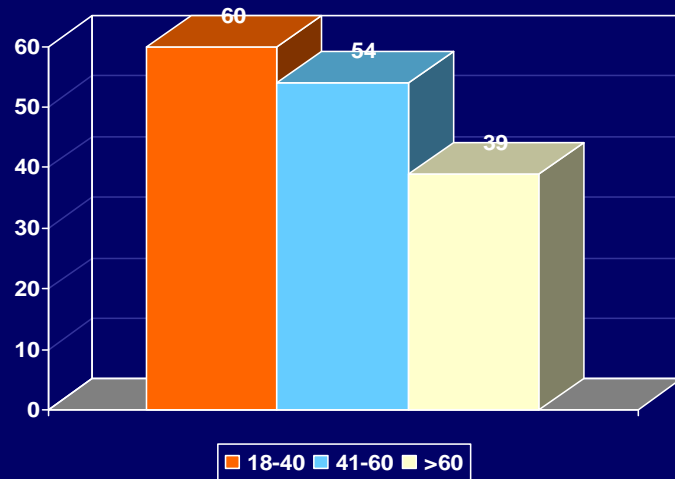


Baseline QOL Scores

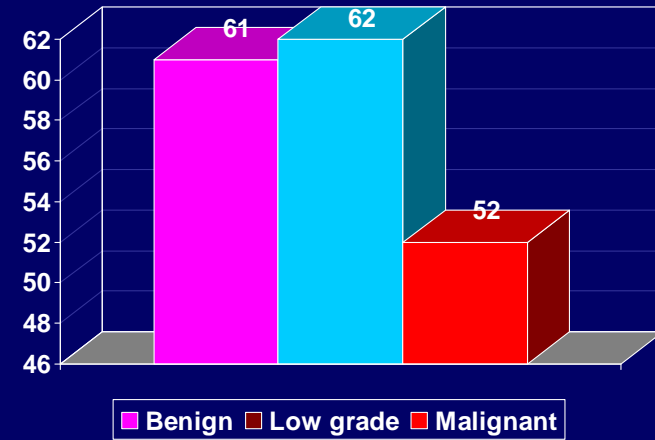
QLQ: higher score - better

Domains	No of pts.	Mean	Std Deviation
QLQC30			
Physical Functioning	243	80	20
Role Functioning	242	78	26
Emotional Functioning	240	65	27
Cognitive Functioning	241	70	28.5
Social Functioning	240	70.5	33
BN 20			
		BN 20: lower score - better	
Future Uncertainty	243	19	20
Visual Disorder	243	18	19
Motor Deficit	243	28.5	22.5
Communication	243	31	26

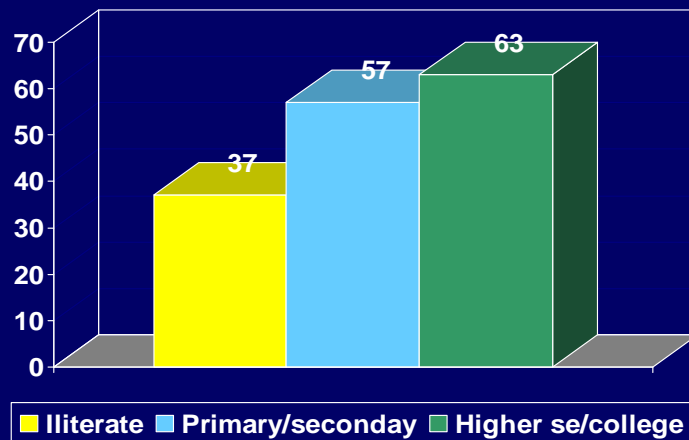
Baseline Global QOL



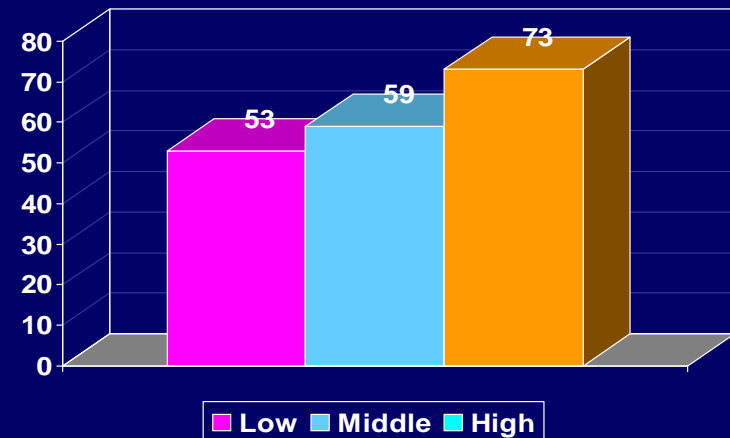
Age



Tumour type



Literacy

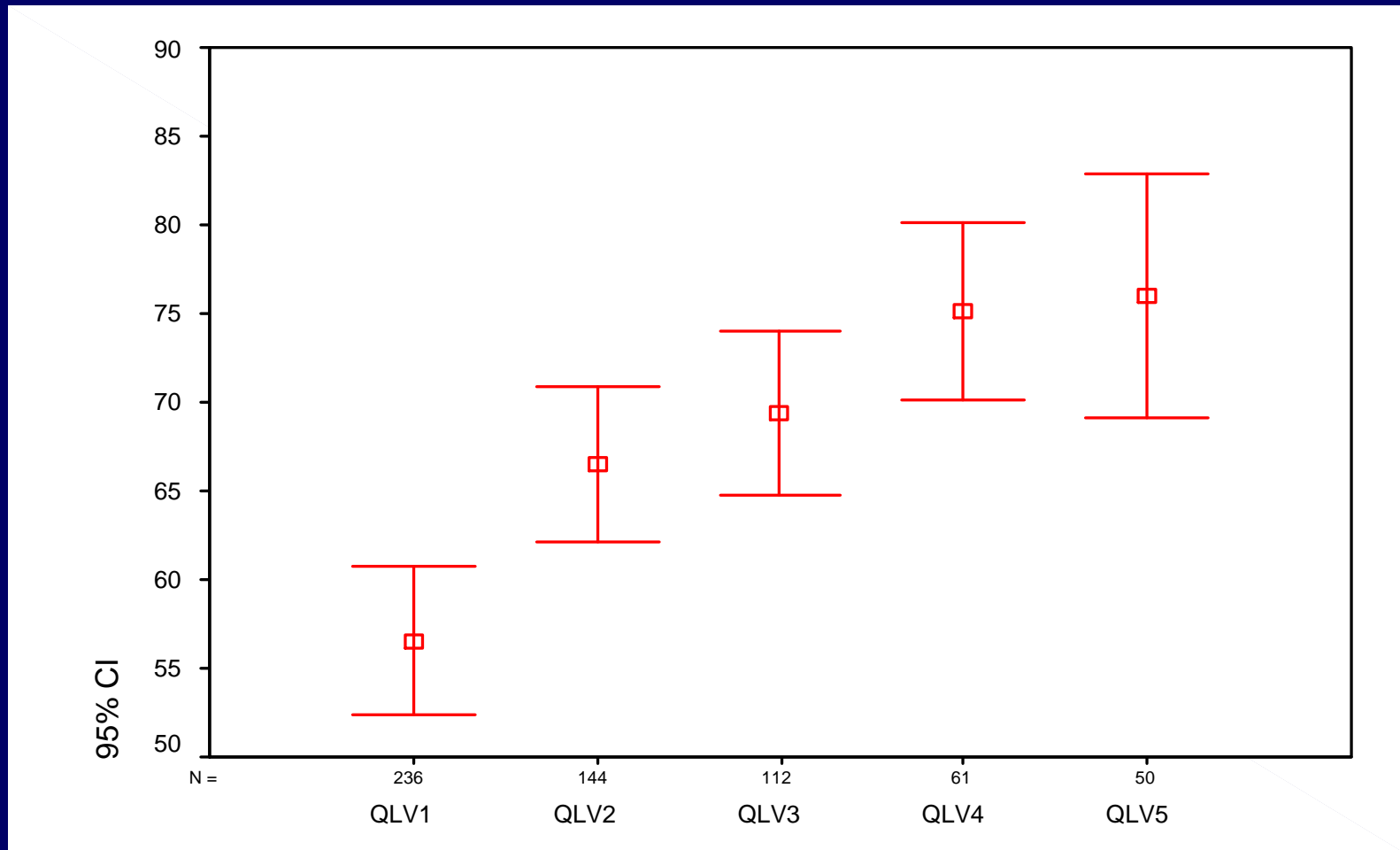


Socioeconomic status

Global QOL

Minimum score: 0

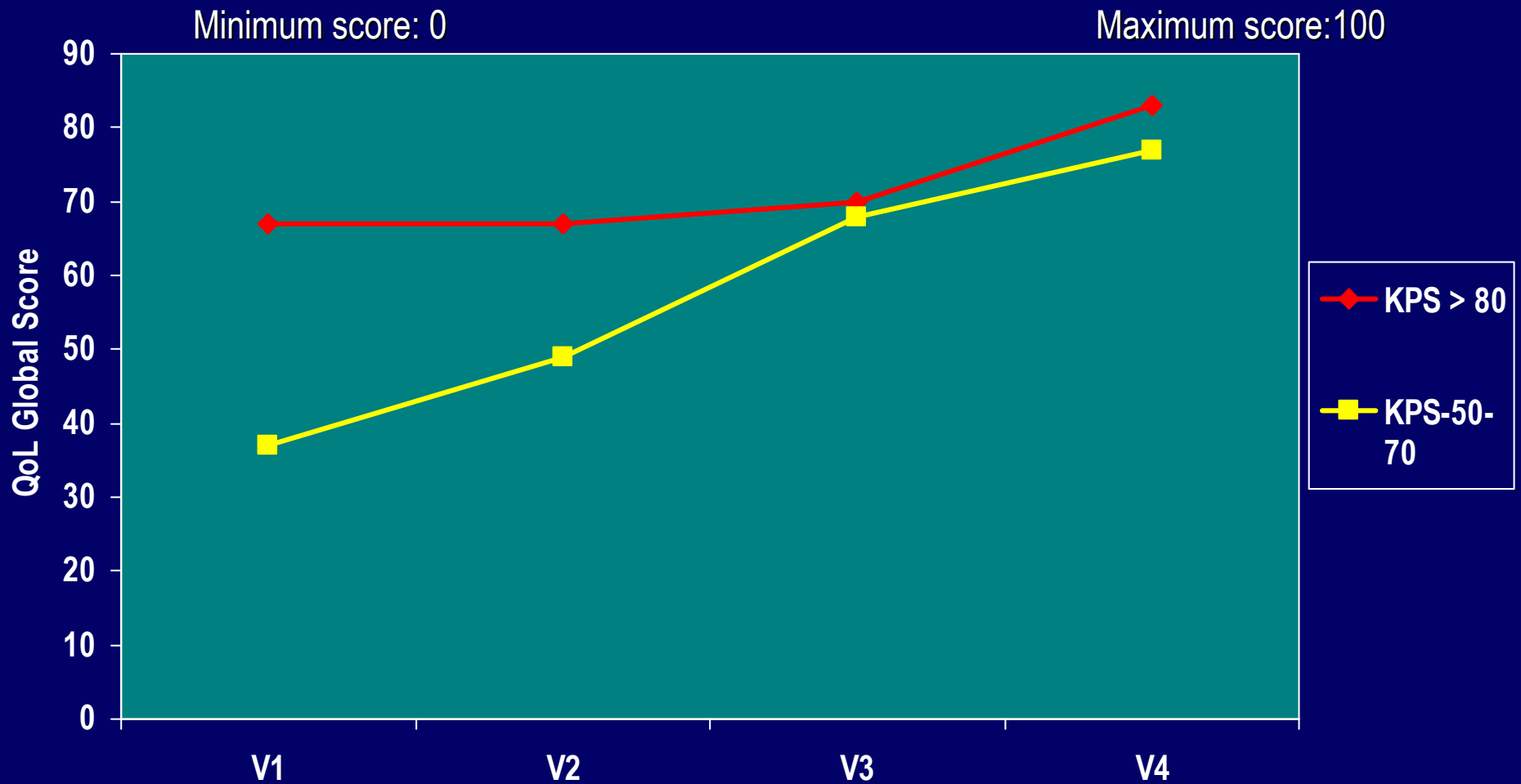
Maximum score: 100



V1 and V3: $p = 0.043$

HIGH SCORE IS BETTER

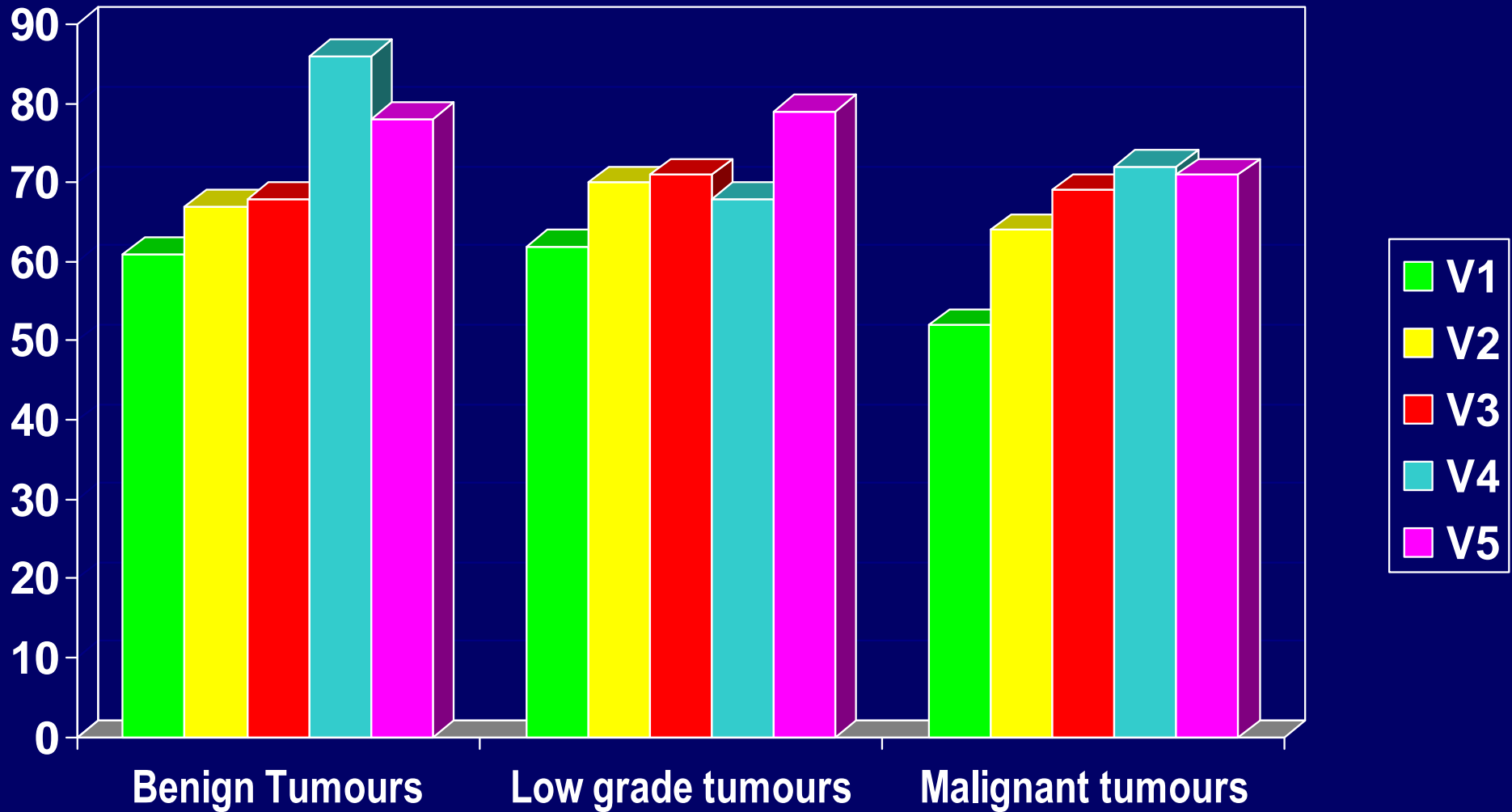
Global QOL and performance status



KPS 50-70: Baseline V1 & 3 months V3: $p = 0.012$

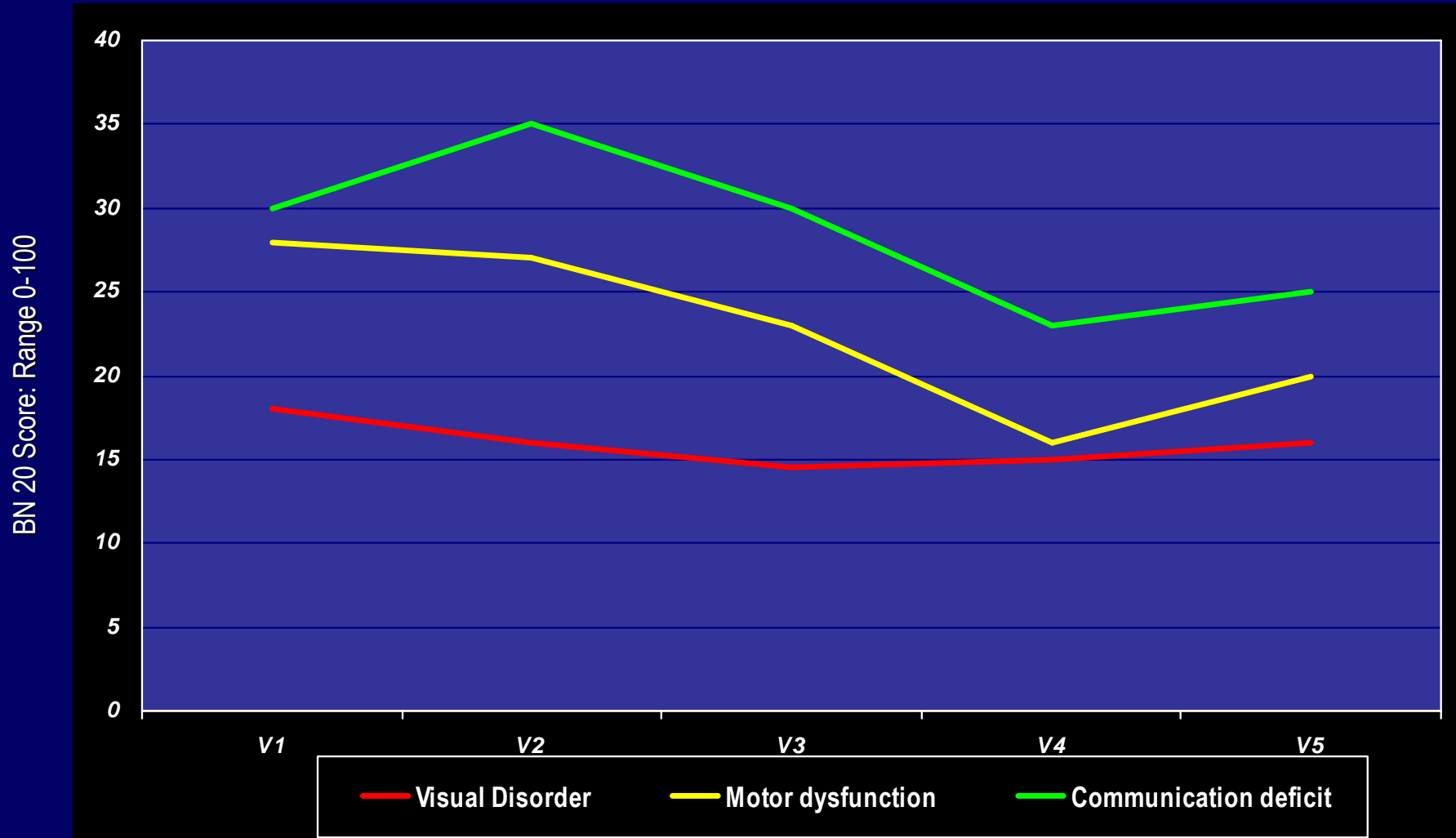
HIGH SCORE IS BETTER

Global QOL and Tumour type



HIGH SCORE IS BETTER

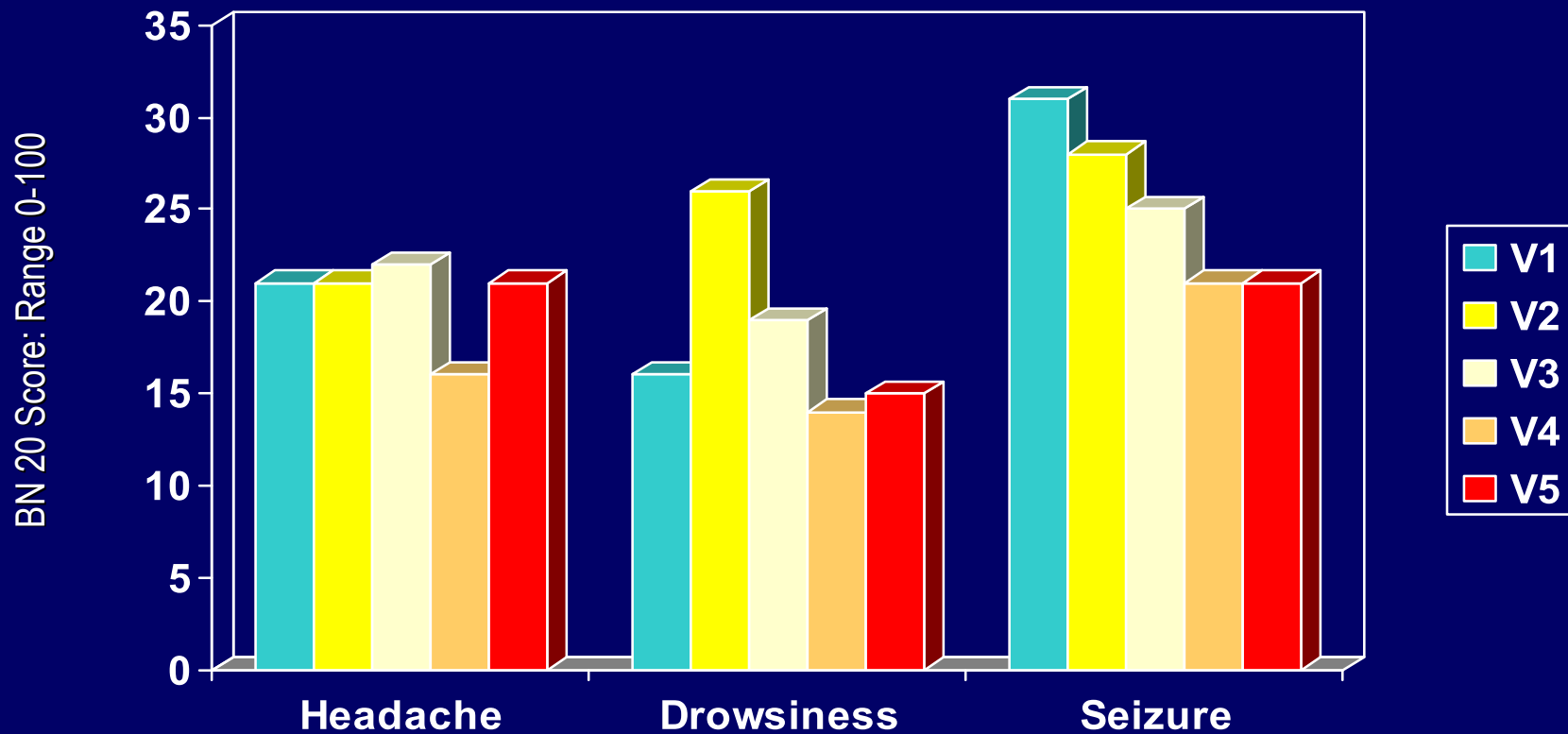
BN 20 Domains



- $p = 0.04$ V1 & V3
- $p = 0.000$ V1 & V4
- $p = 0.015$ V1 & V2

LOW SCORE IS BETTER

Symptom scales: BN 20



Drowsiness: $p = 0.001$ V1 & V2

Seizures: $p = 0.009$ V1 & V3

Other symptom scales: $p = ns$

LOW SCORE IS BETTER

Conclusions

- Patients with brain tumours before starting adjuvant therapy have relatively low quality of life,
- Age more than 60, malignant tumours, low socioeconomic status and poor education are likely factors to be associated with poor QOL scores at baseline
- Brain Cancer module domains seem to be more appropriate in measuring QOL than QLC core questionnaire
- Radiotherapy (post-operative and upfront) improves global QOL of patients, especially in motor and communication deficits
- Maximum improvement seems to be seen in patients with baseline low performance status and malignant tumours
- There is a transient deterioration in drowsiness and nausea and vomiting following radiotherapy
- QOL evaluation in routine practice is feasible; however needs dedicated personnel and follow up evaluations in controlled fashion
- Efforts should be made to minimise administrative errors

Acknowledgements

- Rakesh Jalali
- Rashmi Kamble
- Sachin Parab
- Anagha Kakade
- Kalpesh (deceased)



www.tatamemorialcentre.com



www.braintumourindia.com

Brain Tumour Foundation of India

Patients

If you have brain tumour or have a loved one suffering from it, you'll find a lot of information here.

Doctors

This is the doctor's meeting place. If you're a doctor looking for information on brain tumour, please enter here.

We shall overcome



BRAIN TUMOUR FOUNDATION
www.braintumourindia.com

BTF

The Brain Tumour Foundation of India is a non-profit organisation committed to minimise the physical, emotional and financial suffering associated with the diagnosis, treatment and rehabilitation of patients with brain and spine tumours, and their families

Support Team

At BTF, we can always do with some help. If you have anything to offer these victims of brain tumour, check this link out.



Brain Tumour Foundation of India

74, Ground Floor, Main Building, Tata Memorial Hospital, Parel, Mumbai - 400 012, INDIA

Tel: 91-22-2417 7153 / 2417 7159 . Fax: 022-2417 7159 / 2414 6937

Pager: dial 9602 and ask for 135135 or 122122

Email: btf@braintumourindia.com

