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Research Article

# AWARENESS AMONG PEOPLE BASED ON NEURO ONCOLOGY

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## ABSTRACT

Limitations in trial design, accrual, and data reporting impact efficient and reliable drug evaluation in cancer clinical trials. These concerns have been recognized in neuro-oncology but have not been comprehensively evaluated. We conducted a semi- automated survey of adult interventional neuro-oncology trials, examining design, interventions, outcomes, and data availability trends. Trials were selected programmatically from ClinicalTrials.gov using primary malignant CNS tumour classification terms. Regression analyses assessed design and accrual trends; effect size analysis utilized survival rates among trials investigating survival.

## KEYWORDS

Primary Central Nervous System malignancies; clinical trial design trends; trial accrual; treatment effect size assumptions; leveraging of trial registry data. Interdisciplinary; Iran; NOSC; brain tumours; neuro-oncology.

## INTRODUCTION

Despite important advances in the molecular understanding of malignant primary CNS tumours and efforts to translate these advances into clinical benefit, there has been limited progress in treatments across neuro-oncology. Therapeutic drug development in neuro- oncology is complicated by a unique set of challenges including vast inter- and intra-tumoral heterogeneity, complex interactions of the tumour with the neuronal and tumour microenvironments, the existence of the blood-brain/tumour barrier which limits the penetrability of compounds, a distinct and isolated immunologic locale, and the inability of preclinical models to recapitulate this complexity. Beyond scientific challenges, past studies have pointed to shortcomings in clinical trial design (including a lack of randomization, absence of controls, overly restrictive eligibility criteria, and low accrual) as contributing to the translation failure of potentially promising therapies.

discussions have highlighted the need to address design challenges through novel trial designs that the scope of our survey included past, ongoing, and planned trials assessing interventions on any malignant CNS tumour diagnoses; we evaluated trial design characteristics, estimated treatment effect size assumptions implied by the trial designs, overviewed the extent of data availability, and summarized reported efficacy and toxicity of interventions.

Research and practice of neuro-oncology compiles clinical neuroscience expertise from neurosurgery, radiation oncology, neuroradiology, medical oncology, neuropathology and related disciplines to optimize planning and therapy in central nervous system malignancies. Such an interdisciplinary context prompted health-care providers from all related disciplines to establish the Neuro-Oncology Scientific Club (NOSC) in Iran and let it flourish since 3 years ago. With the advent of advanced technologies and through continued share of experience, NOSC members have tried to provide more integrated diagnoses and therapeutic care to brain tumour patients across the country. NOSC activities revolve around some key tenets including dissemination of education and updates, facilitation of institutional collaborations; data registry and patients' awareness. By virtue of recent insights on molecular characterization of brain tumours such as codeletion of chromosomes 1p and 19q in anaplastic gliomas and O6-methylguanine-DNA methyltransferase (MGMT) promoter methylation in glioblastoma, a range of translational research is being followed within NOSC. The most recent NOSC meeting which was held in Tehran, recapitulated main advances and dealt with the current debates on functional neurosurgery, biological markers and neuroimaging, risk prediction models in high grade gliomas and clinical issues in paediatric neuro-oncology. This article gives an overview of current hotspots in neuro-oncology research and practice which are pursued within NOSC [1].

Survivorship has become a significant topic within oncologic care. The tools and means by which the provision of survivorship care can be implemented and delivered are in development and are the focus of significant research oncology-wide. These tools and methods include innovations of survivorship care delivery, survivorship care plans, and improving communication among all stakeholders in an individual patient's care as the means to elevate health-related quality of life. The merits of these survivorship care provisions in the field of neuro-oncology and its patients' exigent need for more patient-centric care focused on living with their illness are discussed. Brain metastases occur commonly in patients with advanced solid malignancies. Yet, less is known about brain metastases than cancer-related entities of similar incidence. Advances in oncologic care have heightened the importance of intracranial management. Here, in this consensus review supported by the Society for Neuro-Oncology (SNO), we review the landscape of brain metastases with particular attention to management approaches and ongoing efforts with potential to shape future paradigms of care [2].

Adolescents and young adults (AYA) comprise a specific group of oncology patients with a distinct biological and epidemiological spectrum of central nervous system neoplasms. It has been well documented that they differ clinically, especially in relation to prognosis and chemotherapy tolerance; however, the underlying reasons for this are unclear. Recent advances in the genomics of both childhood and adult brain tumors have provided new explanations and insights into the previously described age-dependent heterogeneity. Herein, we summarize the current state of the AYA population in neuro-oncology, specifically how biological advances can help personalize therapy for this unique group of patients.

The management of brain tumors developed in adolescents and young adults (AYAs) is challenging because of their histological heterogeneity and low incidence. The brain tumor and its treatment interventions can negatively affect neurological, neurocognitive, and endocrinological function, and dramatically affect the circumstances of AYA patients progressing to further education, employment, and marriage. Specific support is thus necessary to maintain the quality of life (QOL) of AYA brain tumor patients. AYA patients and survivors require active intervention and support for returning to school or work, progressing to further education, finding employment, and preserving fertility. Recent cancer genome profiling revealed that AYA gliomas include pediatric- and adult-type genetic alteration. Insights into the biology underlying the distribution of tumors in AYAs may influence the development of prospective trials. A more individualized view of brain tumors may influence stratification of patients' in future clinical studies as well as selection for molecular targeted therapy.[3]

Selection and measurement of appropriate outcomes in clinical trials is critical. A trial or study outcome is a measurable variable examined in response to a treatment or intervention, to assess effectiveness or harm. Traditional measures of response or time-dependent metrics are important (Eg., radiological tumor response or survival), but are somewhat limited because they fail to characterize the functional or symptomatic effect of the tumor on the person. Outcomes should measure, either directly or indirectly, how patients feel, function, and survive. Patients want to live longer, but not necessarily at the expense of quality of life.

The US Food & Drug Administration (FDA) describe four categories of clinical outcome assessment (COA): patient-reported (eg, health-related quality of life by questionnaire), clinician-reported (eg, performance status), observer-reported (eg, informal caregivers), or performance outcomes (eg, neurocognitive tests).Brain tumor clinical trials increasingly include the measurement of patient-reported outcomes, but the level of reporting may be suboptimal.

COS should only be developed for neuro-oncology if there is a clearly identified need and future uptake is anticipated. Examples of need include standardizing outcomes to allow meta-analysis and generation of new knowledge, or identifying outcomes of core importance to patients that are not currently measured in clinical trials—a scenario which may result in treatment recommendations that are not acceptable to patients. COS are increasingly being developed for routine practice which may also justify need. Future uptake requires broad engagement of healthcare professionals conducting neuro-oncology research. The COS should be widely disseminated through conference presentations, publications, and communication with policy makers, charities, and patient organizations [4].

The Core Outcome Measures in Effectiveness Trials (COMET) initiative brings together people interested in the development and application of COS. New COS projects should be registered, and if the same COS are listed as under development by another research group or if overlap exists, COMET facilitates communication between research groups to promote collaboration and prevent duplication of effort and research waste [6].

The existence of a COS with similar scope to one planned does not constitute an absolute contraindication to its development, and may be beneficial within neuro-oncology. Consider the hypothetical situation of a disease-specific COS being developed for pediatric medulloblastoma, and a researcher developing a broader COS defining outcome measures for clinical trials of surgically managed posterior fossa tumors. The disease-specific COS may include outcomes highly relevant to medulloblastoma key stakeholders, eg, disease-specific treatments such as adjuvant chemoradiotherapy. However, a broader COS that reflects surgical intervention for a particular anatomical location (ie, posterior fossa), will identify adverse events associated with surgery that will be relevant to other key stakeholders, including those invested in medulloblastoma. The combination of a disease-specific and treatment-specific COS will cover outcomes of relevance to all key stakeholders [7].

CNS tumors are the most common solid tumor in those aged 0–19 years, represent 6% across all ages, and are the most common cause of cancer death in this population. Pediatric brain tumors are associated with high morbidity which may have lifelong consequences for survivors, both from the disease and treatment. Classifying and reporting postoperative morbidity in pediatric brain tumors is challenging. The disease area is highly heterogeneous, anatomically distributed, and associated with location-specific morbidity. Pathology may also dictate the aggressiveness of surgical intent and the level of postoperative morbidity which is acceptable to achieve adequate disease control. In addition, presurgical neurological condition and co-morbidity status can be variable at diagnosis and may contribute to cumulative postoperative morbidity. Finally, many children will go on to have systemic therapies or radiotherapy which also affect tumor-associated morbidity. Transparent and reproducible morbidity reporting helps to manage patient and parent expectations, provides a standardized way to compare adverse events in clinical or research studies and provides a benchmark to compare clinical services. The application of existing morbidity tools to report pediatric brain tumor surgery harms is inadequate. The COMBAT project will develop a core set of adverse outcomes for children undergoing tumor biopsy and/or resection which are determined to be of importance to all key stakeholders [5].

Neuro-oncology and palliative care: a challenging interface Palliative care is defined by the World Health Organization as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” Palliative care encompasses symptom control and provision of practical support to patients and their carers—from first referral through terminal care and death and into bereavement.

The goal of palliative care is to maximize quality of life, drawing on the skills of a multidisciplinary team to help the patient live as actively as possible whilst neither hastening nor postponing death. Palliative care can play an important role in the management of malignant and nonmalignant conditions, in both inpatient and outpatient settings [6].

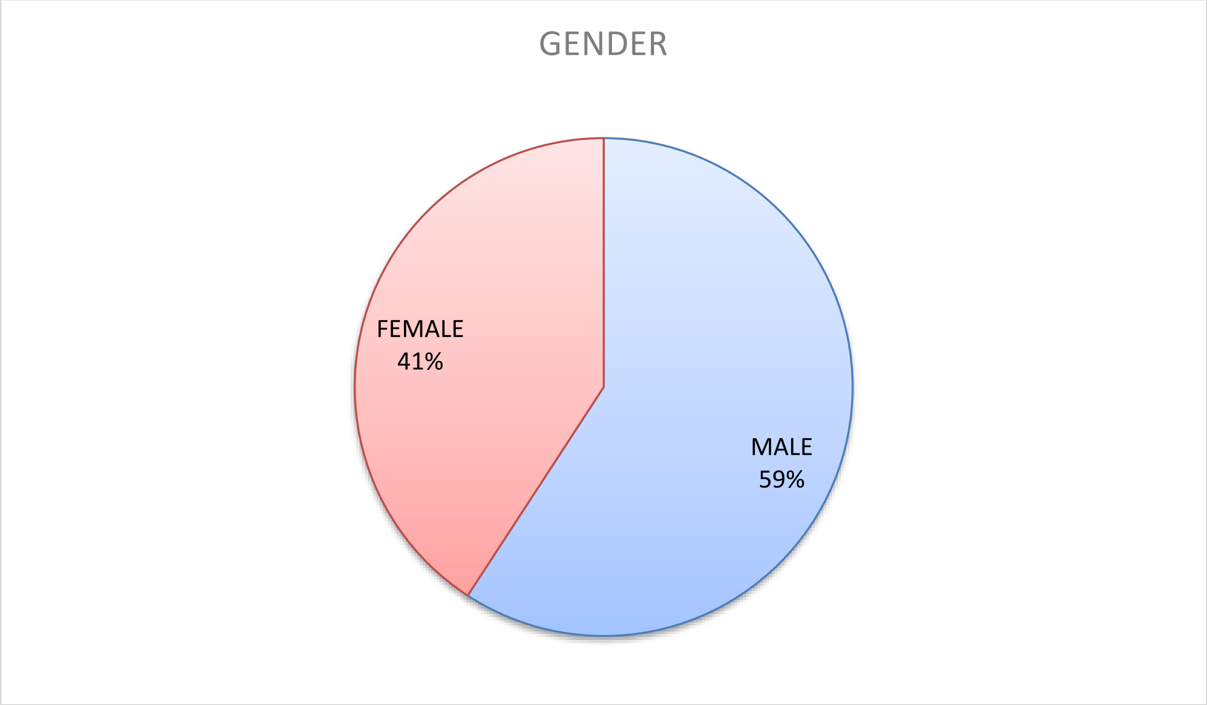
## MATERIALS AND METHODS

This study used an online google forms questionnaire as the instruments. Invitation to people in this survey was sent through via email and among social media platforms. It was sent this way because everyone nowadays are on social media platforms it would be easy to spread awareness in this way. Therefore, using Google form to reach each participant is the best choice.

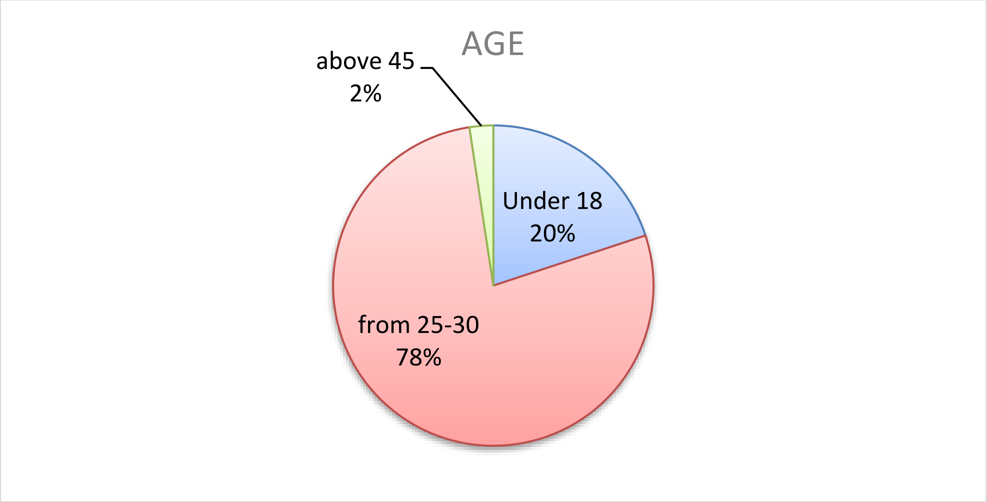
The target respondents are the young people of Tashkent, Uzbekistan and India under the age of 25 because the young people ratio are more in this area and they need a good awareness among them . The questions in the developed questionnaire were distributed for this pilot to test the awareness of public on neuro-oncology. The population of this survey was 102 members. This work is done to create awareness among people on neuro oncology. The search for literary sources was carried out using the bibliographic databases Web of Science, Scopus, DBLP, PubMed. When selecting sources, they paid attention to experimental articles, literary reviews, the number of their citations over the past year.

## RESULTS

The survey were conducted using information and communication technologies, booklets, brochures, presentations, etc. All were asked to answer using a specially designed public awareness on neuro-oncology questionnaire. The table below show the results of the survey. People of about 102 were under survey. Among them, Male (40.8%), Female (59.2%) and Others (0%)

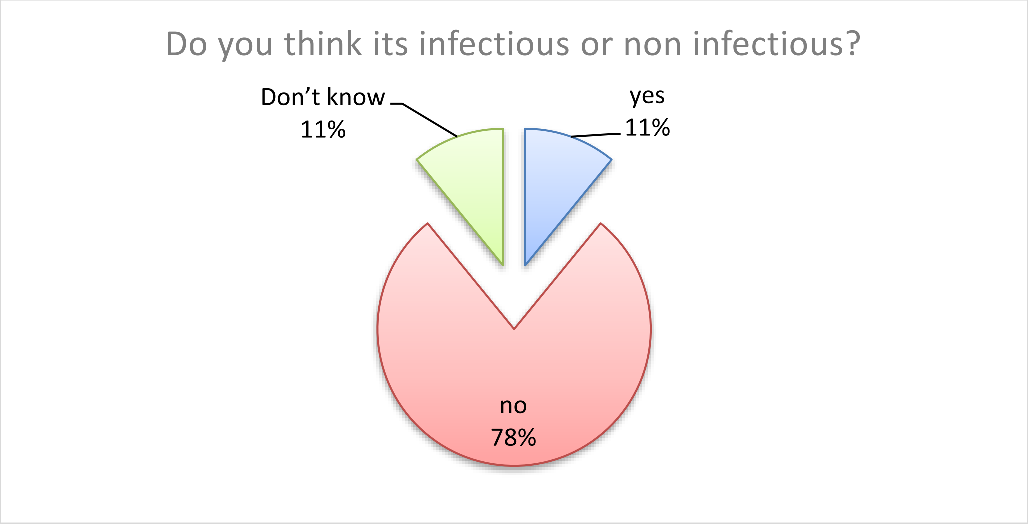


The age of the participants was from 18-25 years old (78.4%), from 26-40years old (13.7%), from 41-60 years old (7.8%) and from 60 and above (0%). The respondents are mostly under 25 because my survey reached to most of the young people whom I'm in contact with. Even-though , I also received response from middle-aged people through my family members and relations in India .

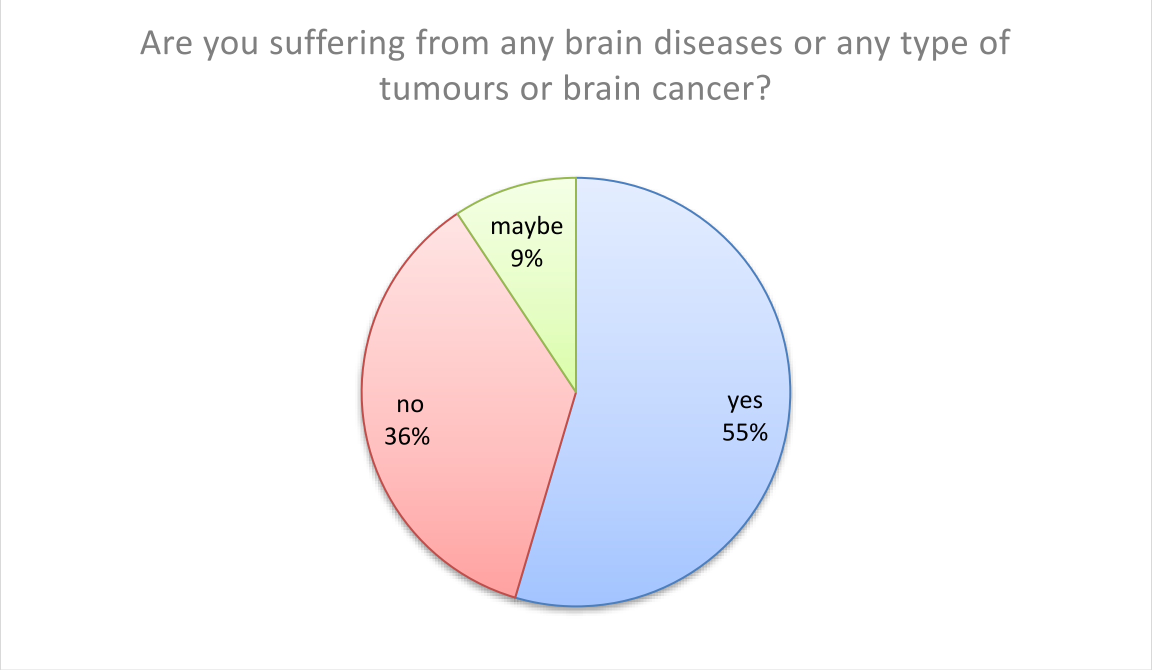


Most of the participants of the survey responded the correct answer 'No'(78%).

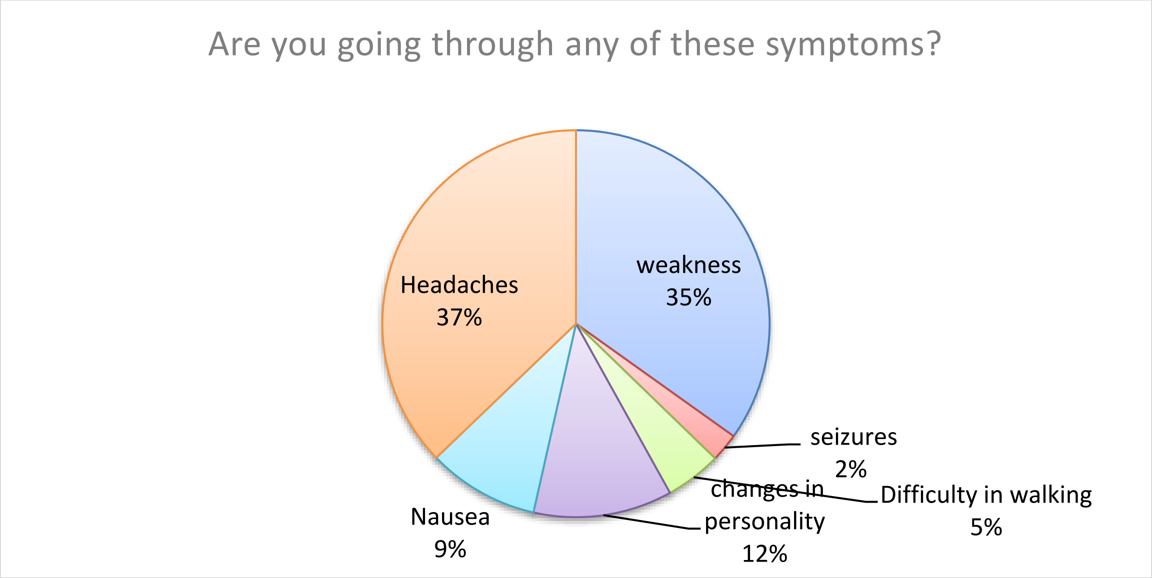
So the result tells that the disease is not contagious by the people. Even-though, some people are not aware that it is not infectious and answered as 'Yes' (11%)



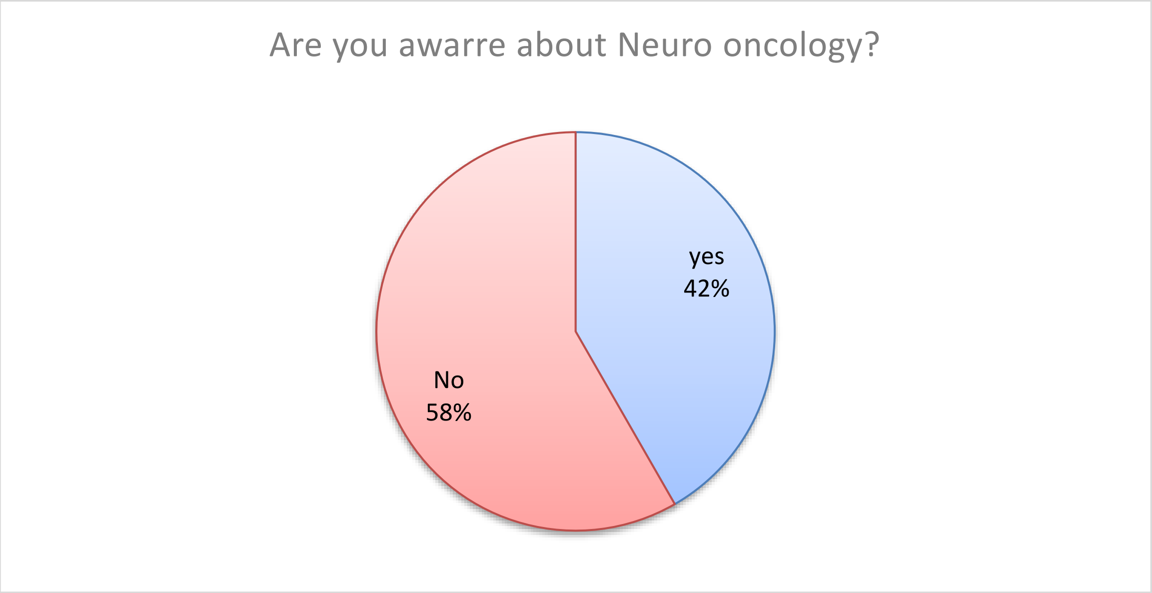
So more than half (55%) of the people in my survey are suffering from any kind of brain related diseases. So this portrays that these diseases are becoming familiar in our life cycle nowadays.



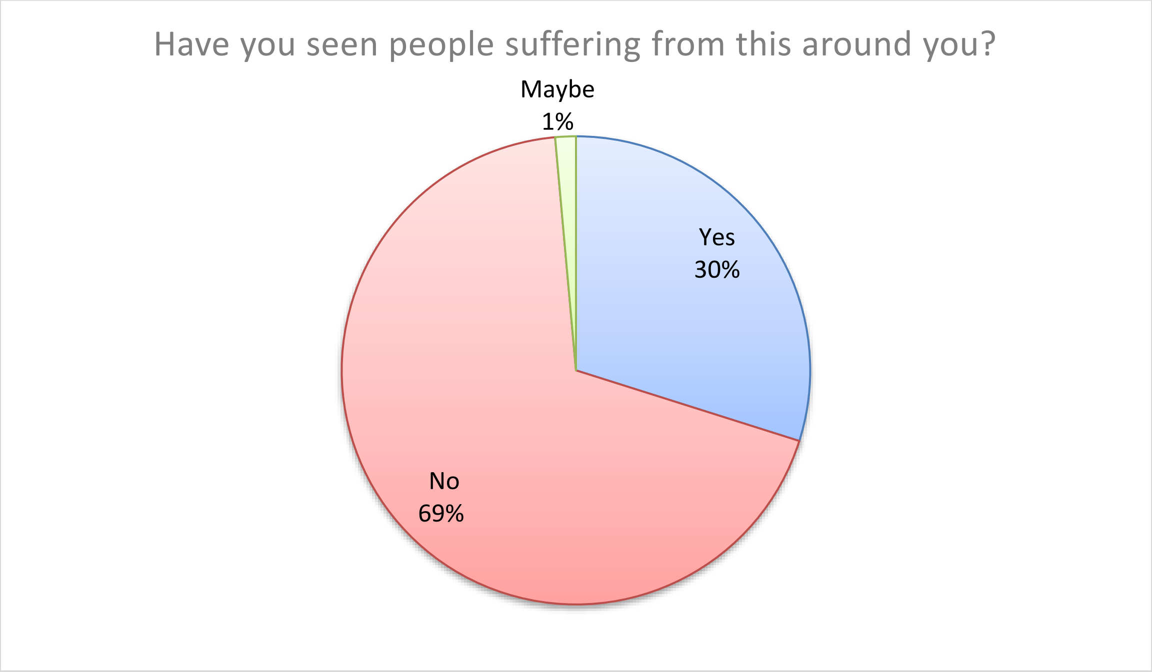
Nowadays Headache (37%) became an usual symptom among teenagers and adults because of lots of stress they go through in this era. Due to this the cycle continues as Weakness (35%) ,Change in personality (12%) ,Nausea (9%) and goes on.

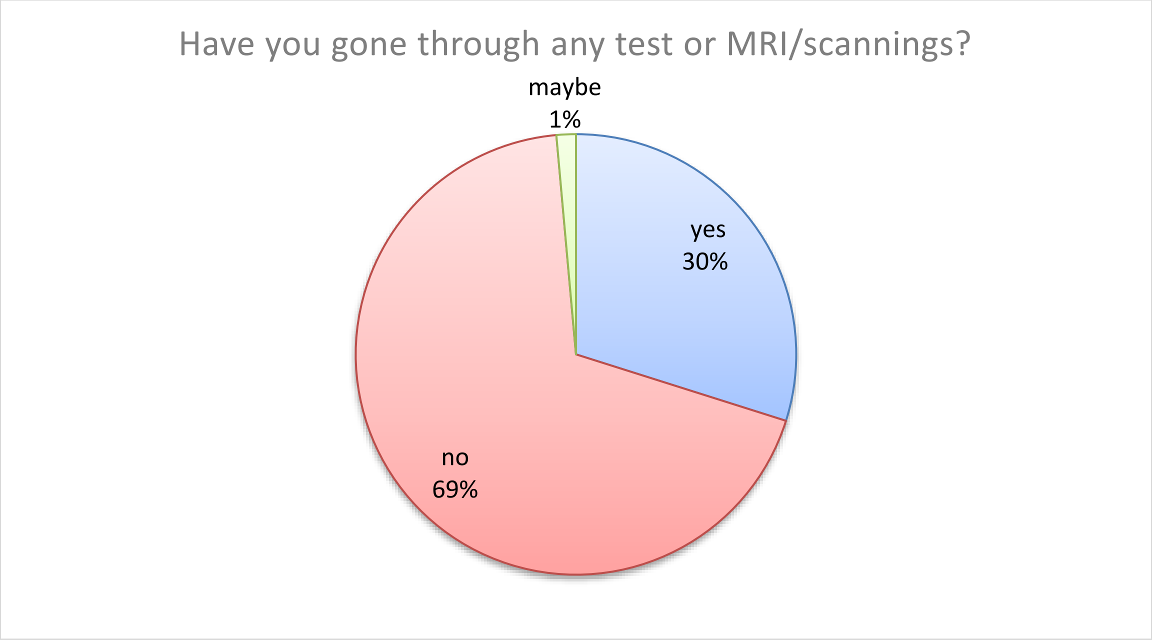


Most of the people doesn't know about Neuro-oncology and they are not aware about this disease.

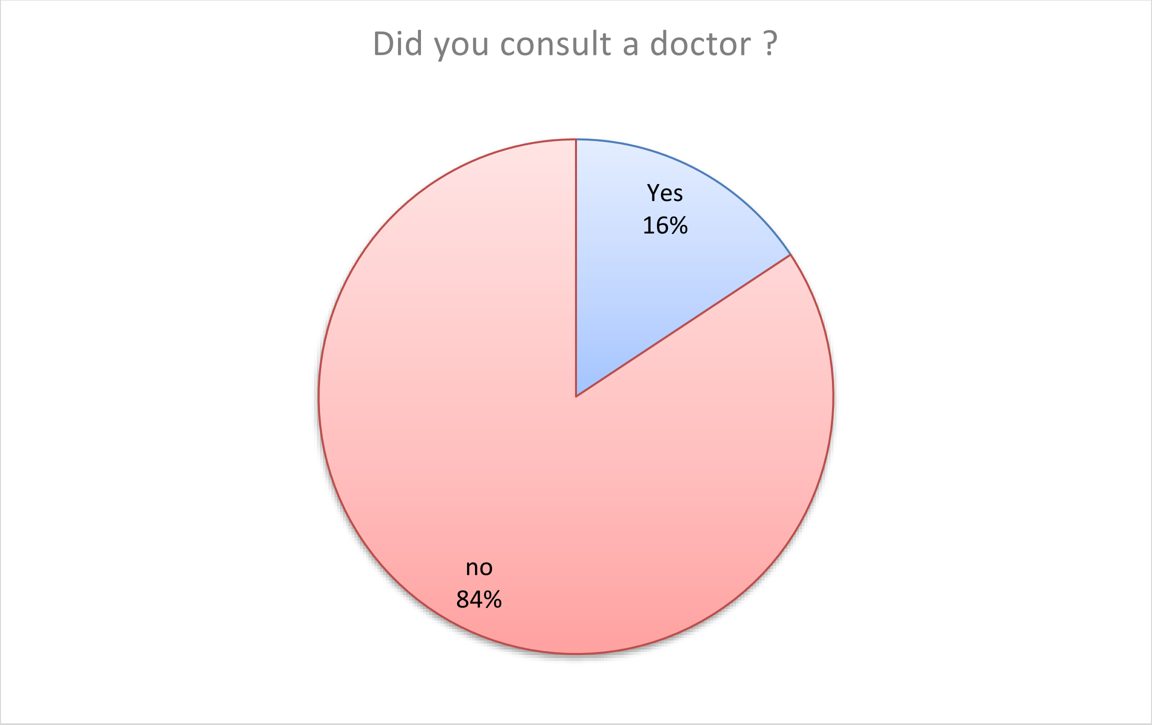


It’s not a prevalent disease in this era because people never share that they have any oncology disease (69%).

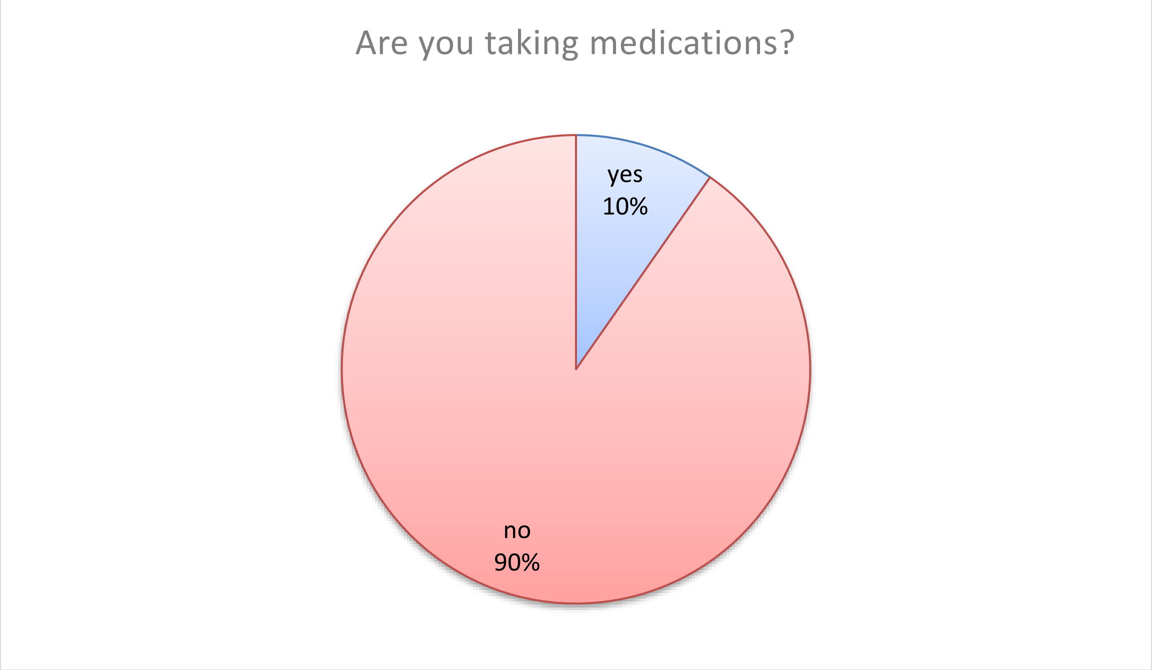




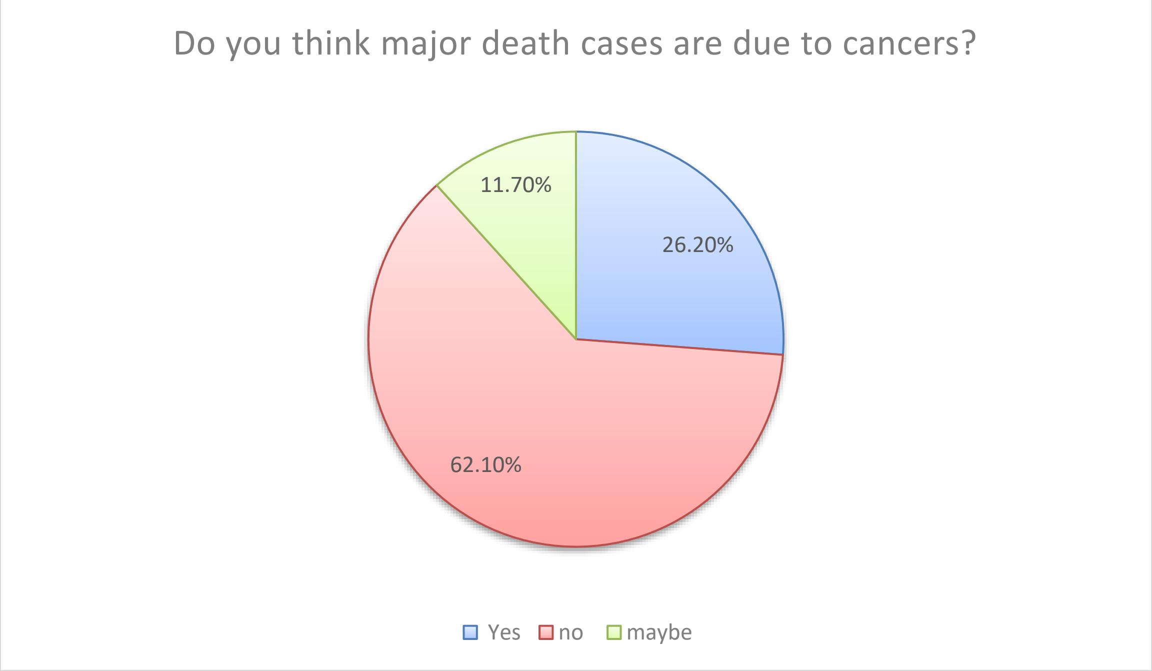
MRI Scan are becoming very common but even then people get fear while performing those tests so they don't prefer to take tests even though they have the related symptoms so that we got the answer mostly as 'no'(69%)



Moving to Neurologist now is not usual because most of the people said 'no' (84%) . They move only if the general doctor gives an expert opinion.



No relevant disease observed so ultimately they prefer no (90%) medications. Very rare case are prevalent so they might take medications (10%).



In this survey we can see most of the people knew about neuro oncology and its common symptoms. Tumors, brain cancers is a common neurological disorder characterized by recurrent headaches. Typically, the associated symptoms affects a person so much as it's all basic signs a person can suffer from nausea, difficulty in walking, headaches, changes in personality etc. The pain is generally made worse by physical activity during an attack, although regular physical exercise may prevent future attacks. Up to one-third of people affected have aura: typically, it is a short period of visual disturbance that signals or harmful radiation will effect it. Occasionally, aura can occur with little or no following symptoms ,but not everyone has this symptoms.

## DISCUSSION

When analyzing the efficiency of knowledge assimilation, the compared options, in contrast to the analysis of minimizing costs are characterized by greater or lesser, but not equivalent, efficiency.

In this regard, it is important to assess the degree of feasibility of the analysis, depending on the level of reliability of the data. The test results were expressed in points Participants' results were calculated using Microsoft Excel software. The assessment of the effectiveness of the assimilation of knowledge was calculated based on the application of the proposed methodological recommendation in practice Thus, each participant of the survey, on average. Increased his theoretical and practical level of knowledge in the field of Neuro Oncology and it's prevention by almost half.

## CONCLUSION

Its concluded from my survey also that many people nowadays are going through common symptoms but weren't aware about it. Now after participating in my survey they would have got more awareness than before. If people are receiving any kind of symptom they should obviously consult the doctor as soon as possible. They shouldn't take risk in it because the death rate in this case are literally very high and no proper medication can work if the condition goes out of hand .

## RECOMMENDATION

- Avoid environmental hazards such as smoking and excessive radiation exposure
- Manage stress
- Relaxation techniques like meditation, yoga and mindful breathing can help
- Eat on a regular schedule
- Drink lots of fluids
- Get plenty of rest
- Get regular moderate exercise
- Ask your doctor about preventive medicines if you get
- Try getting lots of oxygen

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