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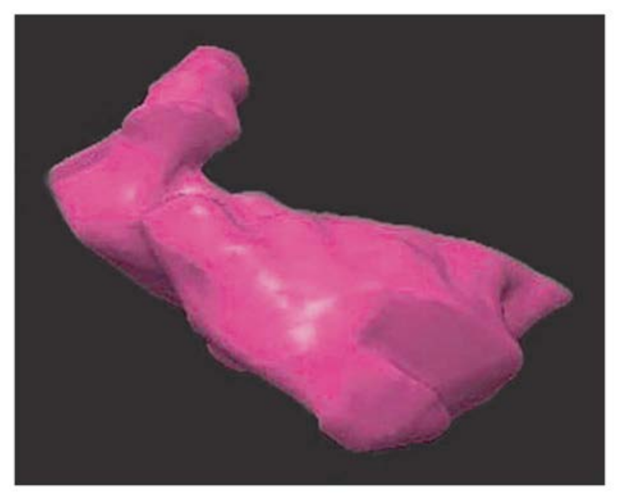

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# Psychosocial Care for Neuro-Oncology Patients, Results of a Survey on Behalf of EANO

Hanneke Zwinkels

## Introduction

Patients with malignant brain tumours are confronted with a disease with a poor perspective and hardly any chance for cure. With poor prognosis and possible cognitive and physical decline brain tumours affect quality of life and this reflects a need for psychosocial and supportive care. Clinicians responsible for treatment within a multidisciplinary team are able to refer patients and their partners for psychosocial care to oncology nurses, social workers, (neuro-) psychologists, physiotherapists, and speech therapists. These health care professionals can play a key role by guiding patients and their family carers from diagnosis until death, paying attention to the side effects of treatment and its influence on quality of life. Although this supportive care is still limited to certain medical centres, there is increasing interest in neuro-oncology as a sub-specialty for other health care professionals. EANO would like to encourage collaborations between different specialties and the focus on the availability of supportive care.

## Background

A lot of – mostly observational – studies reflect the increasing attention for supportive care needs in patients with brain tumours. Recently, 2 reviews were published describing the knowledge on patients' psychosocial needs and the type of care that has been found to be beneficial. Looking at the patient's and caregiver's perspective, Sterckx et al [1] state that both patients and caregivers report many emotional, instrumental, and informational needs, but that they are dissatisfied with the received support or because of lack of adequate support. From a clinical perspective, Ford et al [2] conclude that there is a need to refine understanding of patients' and caregivers' experiences and needs, and to better tune care to their needs.

But do we know which care is available and where? From a UK study in which clinicians from multidisciplinary neuro-oncology teams were approached to get insight into available care, it became clear that more than 80 % of the respondents (n = 86) reported having referral access to neurologists, physiotherapy, speech therapy, and clinical trials. Fewer clinicians (60–70 %) were able to refer to an epilepsy nurse, a social worker, counsellor, neuropsychologist or support group, or for rehabilitation, occupational therapy, or complementary therapies. The least accessible service was clinical psychology (50 %) [3].

## Methods

On behalf of EANO, e-mails were sent out to its members with the aim to evaluate which health care professionals provide this supportive care in an attached survey. In this way, clarity on the available supportive care throughout Europe could be established. Analysis of the received surveys was performed with SPSS 17.0.

## Results

Approximately 350 e-mails were sent, which resulted in received surveys on delivered psychosocial care from 60 health care professionals (HCP); 20 % were clinicians, 42 % nurses, 10 % social workers, 18 % psychologists, 6 % neuropsychologists, 2 % speech therapists, and 2 % physiotherapists. The number of respondents per country: the Netherlands 24 (13 nurses), United Kingdom 8 (7 nurses), France 7 (2 nurses), Italy 6 (1 nurse), Belgium 4, Germany 3 (1 nurse), Spain 3, Sweden 2, Denmark 2 (1 nurse), and, finally, Austria 1. The mean age of clinicians (n = 12) was higher than that of nurses, the mean age of nurses (n = 25) was higher than the mean age of paramedical HCPs (n = 23).

Most HCPs provide care for patients with primary as well as secondary brain tumours (78 %), whereas 3 % only provide care for secondary brain tumours. 40 % of the HCPs provide care for patients with spinal cord tumours while 33.3 % do so occasionally. 25 % of the total respondents provide care for children.

Psychosocial and supportive care most importantly consist of support and information on symptoms and conditions, social aspects and coping; to a certain extent, other aspects such as medication, anti-epileptic drugs, anxiety and depression, end-of-life phase situations and existential problems were mentioned (Table 1), depending on the profession of the HCP. In all surveys received from nurses, psychosocial and supportive care was offered for both patients and their partners, other HCPs such as physiotherapists and psychologists mainly support patients.

Both nurses and paramedical HCPs provide psychosocial support for end-of-life and existential issues, 84 % of nurses (n = 25)

**Table 1.** Various provider groups and their spectra of support and information.

| | Information of patient on disease | | Patient care during end of life | | Supportive care on existential problems | |
|---|---|---|---|---|---|---|
| | **No** | **Yes** | **No** | **Yes** | **No** | **Yes** |
| Nurse/nurse practitioner | 1 | 24 | 4 | 21 | 3 | 22 |
| Health care provider | 13 | 10 | 10 | 13 | 3 | 20 |
| Clinician | 0 | 12 | 5 | 7 | 6 | 6 |
| **Total** | **14** | **46** | **19** | **41** | **12** | **48** |

compared to 56 % of paramedical HCPs (n = 23) provide care during the end-of-life phase. Two nurses practice in a home care setting, all other HCPs work at an academic or non-academic hospital.

## Conclusion

The results of the received surveys show that in Western Europe there are multidisciplinary teams providing psychosocial care, in the Netherlands and the UK there are more nurses than other health care professionals available for this type of care. However, the e-mails sent out were sometimes undeliverable (approximately 60 of 350), and EANO has less members in Eastern Europe. The results described do not give enough insight into available psychosocial care in Europe, however, for Western European countries it seems that there are more HCPs available.

## Recommendations

Psychosocial oncology focuses on a whole-person approach to cancer care, addressing the social, psychological, emotional, spiritual, and functional aspects of the patient journey through a multidisciplinary team and service providers from various care settings. The disciplines include oncology, nursing, social work, nutrition, psychology, palliative care, psychiatry, rehabilitation, volunteer services, and spiritual care. Psychosocial oncology is an essential service to improve the quality of life for people affected by cancer. The availability of health care professionals working in multidisciplinary neuro-oncology teams could be increased to improve psychosocial neuro-oncology.

Neuro-oncology specialist nurses play a key role by acting as a point of contact for patients, their caregivers, and all other healthcare professionals involved in the clinical management of brain tumour patients. Oncology nurses are the professionals most often available for patients and families as they experience cancer across all settings of care. Oncology nurses play a fundamental role in cancer care, with the potential to influence and improve the quality of care. The position of the neuro-oncology nurses in the multidisciplinary setting is not clearly defined, although their role is recognized as being valuable and expanding. To improve care and care management of neuro-oncology patients development of expertise and education of neuro-oncology nurses is essential [4].

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