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## The need for social support for patients suffering from brain tumour

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### Abstract

**Introduction.** Central nervous system tumours establish a group of benign and malignant tumours stemming from various nervous system cells [1]. In every stage of cancer the patient needs help and support compensating the deficits in psychophysical health. The term “social support” is used interchangeably with the following expressions: help, relationships, bonds, social relationships, connections [5,6].

**Objective.** The aim of the study was to assess the need for social support for patients suffering from brain tumour.

**Results.** For patients suffering from brain tumour the most needed form of support is emotional.

**Conclusions.** There is a relationship between certain sociodemographic data (marital status, family type) and the need for a certain kind of social support (personal or professional/formal support).

**Keywords:** brain tumour, social support

## **Introduction**

Central nervous system tumours establish a group of benign and malignant tumours stemming from various nervous system cells [1]. Intracranial neoplasm can cause nonspecific symptoms, which are usually triggered by intercranialhypertension or focal symptoms related to a local brain damage by the tumour. Chronic intercranial hypertension caused by the tumour can be diagnosed by observation of general symptoms, e.g. headache, vision impairment, drowsiness, dizziness, nausea, vomiting, stiff neck, paresis of abducent nerve or papilledema [2].By far the most frequent general symptom is headache, manifesting itself usually in the morning, with pain increasing in intensity with the increase of the tumour itself. Additionally, nausea followed by vomiting appears, and when the tumour is located in the back of the skull, vomiting without nausea can occur due to irritation of vagus nerve[3,4].In every stage of cancerthe patient needs help and support compensating the deficits in psychophysical health. The term “social support”is used interchangeably with the following expressions: help, relationships, bonds, social relationships, connections [5,6]. Social support plays a major role in sustaining one’s health, protects one from the illness and aids healing process. Different types of social support can be distinguished: emotional, informational, instrumental, assessment and material [5]. Informational support is a process of providing information or advice aiming at solving multiple problems and hardships[7]. The examples of informational support are showing affection, love, care and trust [7]. Assessment support is feedback with regard to how a given person is found and what is thought of them[8]. Instrumental support is a kind of help offered directly to one person, that is: help with work or with household chores, or other service offered directly to the person in need [9]. Material support is direct, physical help for the people in need (material/financial help as well as giving food, offering shelter, providing medicine, etc.)[10]. Social support can be ensured by many providers, such as: personal support (family, friends), formal (charities, institutions, social service, church groups) and professional (medical personnel, specialty care clinics, psychotherapy).

## **Objective**

The aim of the study was to assess the need for social support for patients suffering from brain tumour.

## **Methods**

The study was conducted in 2019 in Neurology Department of Clinical Hospital no. 4 in Lublin. In total, 104 patients with brain tumour were tested. The research tool used for gathering research material was Original Questionnaire comprising both closed-end and open-end questions. In order to determine the health state of the research subjects Barthel Index was used, and for determining pain intensity VAS pain scale was used. The research material was analysed with the use of statistical software IBM SPSS Statistica.

## **Results**

Characteristics of the research group. The group consisted of 52,9% women and 47.1% men. More than a half of the research subjects were between 20 and 55 years old. More than a third of the researched patients were 56 years old and older. The remaining 10.9% of the research group comprised patients below 19 years old. With regard to the marital status; more than a half of the patients were married (54.8%). A significant proportion (27.9%)of the patients were in single state – maids/bachelors. Furthermore, 12.5% of the research subjects were divorced, and 4.8% were widowed.

The results displaying the need of social support for the patients with brain tumour suggest that in the face of the disease the patients need emotional support the most (51.9%), and less

often instrumental, informational and material. During the analysis of the emotional support it was shown that more than a half of the research subjects (63.5%) indicated that family was their most important source of emotional support. Every fifth patient specified friends as the source of this kind of support. A small number of patients indicated psychologists or other hospital staff as their source of emotional support. For 2.9% of the research group strangers were the source of emotional support. The statistical analysis showed that the most of the research subjects expected emotional support from their families (75%). This kind of support is expected from friends by 65.4% of the patients, and this number is similar for the psychologists or other hospital staff (63.4%). The analysis of the types of emotional support received by the patients showed the most frequent responses were attention, understanding and acceptance (42.3%). A third of the research subjects indicated emotional prodding/encouraging to act (33.7%). The remaining 24% of patients specified showing appreciation, praising progress in fighting the disease. According to the patients, the benefits stemming from the received emotional support is mainly reinforcement of psychological resilience (30.8%). About a quarter (27.9%) of the patients suffering from brain tumour believed that such support improved their self-esteem, and 16.3% stated that it improved their mood. 25% of the respondents indicated that emotional support helps in all the aforementioned areas. The analysis of the instrumental support suggests that more than a half of the research subjects specified doctors or nurses as their most important source of the instrumental support (63.5%). The other choices for instrumental support were family/friends, support groups and psychologist/other hospital staff/priest. The biggest number of researched patients expected instrumental support from doctors/nurses (84.6%). 21.7% indicated family/friends as the source of instrumental support, 24% indicated psychologist/other hospital staff/support groups. The support in treatment provision domain was received by 80.7% of patients with brain tumour. 50% of the respondents received help with regard to satisfying basic needs and 48.1% of the respondents received help with regard to coping with the disease mentally. The results of the study concerning informational support showed that more than a half of the research subjects received informational support from doctors or nurses (67.3%). The other indications for informational support were psychologist/psycho-oncologist (19.2%) or support groups and other patients. The most patients declared healthcare workers as the source of informational support (80.8%). The patients rarely expected this kind of support from other groups. About a half of the patients received support in a form of explanation or advice about e.g. the course of the disease or the principles of treatment (51.9%). 1.9% of the research subjects received information about support groups, and 5.8% pointed out receiving information via brochures and educational materials. The remaining 40.4% of the respondents received all of the above forms of support. For more than a half of the research subjects family was the biggest provider of material support (80.7%). Friends were providers of material support for 27.8% of the patients. 14.4% of the respondents received material support from charities/foundations. As many as 39.4% of the patients indicated that they did not expect any material support.

More than a half of the respondents determined that for the most part they received personal support (e.g. from family or friends) (59.6%). 20.2% of the respondents received formal support. 11.5% of the respondents benefited from professional support. The remaining 8.7% of the patients used the aforementioned forms of support equally.

Pain experienced by the patients was measured by employing VAS pain scale. The average on scale of 0 to 10, where 10 meant highest pain intensity, was 5.59 (SD=2.71). The respondents most often suffered from headaches.

The statistical analysis of the results showed that there is a relationship between the marital status of the patients and the need for a certain source of support. Among the single status patients there was a higher percentage of the ones utilising formal and professional sources of

support. In the group of patients who were married personal form of support was dominant (Tab.1).

**Tab.1. Relationship between the marital status of the patients and the need for a certain source of support**

Marital status	Source of support				
	Personal support (e.g. family)	Formal support (e.g. charity organization)	Professional support (e.g. specialist clinics)	All sources of support to the same extent	In all
The single status	20	13	9	5	47
	42,6%	27,7%	19,1%	10,6%	100,0%
Married personal	42	8	3	4	57
	73,7%	14,0%	5,3%	7,0%	100,0%
In all	62	21	12	9	104
	59,6%	20,2%	11,5%	8,7%	100,0%
<b>Chi-2 =11,251; p=0,010</b>					

There was a relationship proven between the type of the patients' families and the need for a certain source of support. The patients from single-parent families were more likely to use formal and professional sources of support. In the group of patients who were from complete families personal form of support was dominant (Tab.2).

**Tab.2. Relationship between the type of the patients' families and the need for a certain source of support**

The type of the patients' families	Source of support				
	Personal support (e.g. family)	Formal support (e.g. charity organization)	Professional support (e.g. specialist clinics)	All sources of support to the same extent	In all
Complete families	50	11	3	7	71
	70,4%	15,5%	4,2%	9,9%	100,0%
Single-parent families	12	10	9	2	33
	36,4%	30,3%	27,3%	6,1%	100,0%
In all	62	21	12	9	104
	59,6%	20,2%	11,5%	8,7%	100,0%
<b>Chi-2 =17,578; p=0,001</b>					

Statistically significant relationship was observed between the marital status of the patients and the need of emotional support. Among the single patients there was higher percentage of ones who had friends', psychologists'/other hospital staff and other people's support. In the group of people who were married family support prevailed (Tab.3).

**Tab.3. Relationship between the marital status of the patients and the need of emotional support**

Marital status	Emotional support				
	Family	Friends	Psychologist/ other hospital staff	Other people	In all
The single status	16	19	9	3	47
	34,0%	40,4%	19,1%	6,4%	100,0%
Married personal	50	5	2	0	57
	87,7%	8,8%	3,5%	0,0%	100,0%
In all	66	24	11	3	104
	63,5%	23,1%	10,6%	2,9%	100,0%
<b>Chi-2 =32,475; p&lt;0,001</b>					

There wasn't any statistically significant relationship between the assessment of the patients' with brain tumour state of health (with the use of Barthel Index) and their need for a certain source of support. There was no statistically significant relationship between the experience of pain and the need for a certain kind of support.

### Conclusions

The conducted analysis of the original study showed that the most important type of support needed in the face of the disease is emotional support, that we mostly expect and desire from our families. In the study by Balboni, Paulk, Balboni et al. [11] after observing 343 patients with advanced stages of cancer it was concluded that for 70% of the patients emotional support was the most important value [12]. The study also emphasized that the most important source of emotional support are family and friends (23.1%). The data is consistent with that gathered by the study conducted in the Department of Public Health in Lublin in 2014 [13].

The following conclusions can be drawn from this study:

For patients suffering from brain tumour the most needed form of support is emotional.

There is a relationship between certain sociodemographic data (marital status, family type) and the need for a certain kind of social support (personal or professional/formal support). Among the research subjects who were single there was a higher percentage of patients utilising formal and professional types of support. In the group of patients who were married personal form of support was dominant. The patients from single-parent families were more likely to utilise formal and professional sources of support. In the group of patients who were from complete families personal form of support was dominant.

The most common source of emotional and material support is family, instrumental – doctors/nurses, and informational – medical professionals from hospitals.

Patients suffering from brain tumour expect emotional support from family, instrumental – doctors/nurses, and informational – medical professionals from hospitals.

No statistical relationship between occurrence of pain and the need for a certain kind of support was observed.

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