

The First Telephone Line for the Psychological Support to Oncological Patients and Their Family Members in Serbia

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SUMMARY

Introduction In October of 2010, Serbian Association for Psycho-Oncology, in collaboration with the Ministry of Health of Serbia and the National Health Insurance has launched the first national telephone line for free psychological counseling and support for oncology patients and their families.

Objective The aim of this study was to present results of the first national telephone helpline for psychological support for oncological patients and their families.

Methods The telephone line for the psychological help and support was available from 10 a.m. to 10 p.m., seven days a week and on holidays. A total of 12 previously educated psychologists were involved, with two on duty in the mornings and two in the afternoons. The basic work principles of the Line were anonymity for users (if they wished), free of charge service available to patients from all of Serbia, careful listening, emphatic reflection on anything communicated by users and adequate counselling.

Results Since the beginning of the project (October 2010 up to April 2011) we received a total of 2,748 calls from across Serbia. Almost half of these calls were repeated calls, as patients asked for continuous psychological counselling. Larger percent (63.9%) of women called, when compared to men (35.4%) who used the Line. Most (52.4%) conversations were categorized as "psychological support and counseling," and as continual psychological counseling work (21.1%).

Conclusion The large number of calls suggests that this kind of public, free service for psychosocial and psychological support to cancer patients is necessary in Serbia.

Keywords: psychosocial support; psychosocial aspects; oncology

INTRODUCTION

Since the cancer experience is a negative life event that requires an enormous amount of effort from patients and their families in order to adapt to the multiple challenges posed by the disease, it is important to understand the psychosocial aspects of cancer and its treatment, and the needs of patients and their families to successfully deal with such a challenge [1]. The holistic approach to cancer treatment includes the participation of psychologists during all phases of the disease [2].

Although the psychosocial dimensions of cancer have been explored in the literature since 1958, it is only over the past 50 years that this area has developed into a specific discipline, known as psycho-oncology [3]. This small but emerging field of care deals with the psychological aspects of care, the training of staff in these areas, and provides expertise in psychological, social, and behavioral quality of life [4]. Psycho-oncology has two dimensions: the first one is the study of the psychological reaction of patients at all stages of the disease, as well as that of family members and oncology staff, and the second one is exploring the psychological, social, and behavioral factors that impact cancer risk and survival [5].

However, psychosocial care and support for patients and their families is not yet standard

care in many cancer treatment centers in the developed world, and is even less available in the developing countries, including Serbia. The fact is that in Serbia psycho-oncology has not been developed to the necessary extent, primarily as a scientific discipline, and therefore there is no systematic, organized, professional and easily "available" psychological support and psychotherapy to help patients who suffer from various forms of malignant disease in all stages of treatment, as well as their family members.

As the very first step in providing the patients and their family members the psychological support, we organized the first national SOS phone line in October of 2010. In this report, we present the first results of this project.

OBJECTIVE

The overall objective of launching an SOS phone line was providing professional psychological support and assistance to cancer patients in all stages of the disease and treatment, as well as to their family members.

Launching the first national psycho-social program of providing organized and professional psychological support and assistance to patients suffering from various malignant diseases through helpline represents the pro-

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motion and provision of a specialized services for cancer patients, as the phone calls are free and available to patients from all over Serbia [6].

Specific objectives of the psychological helpline for oncology patients were as follows:

- Organizing easily accessible, highly professional and specialized psychological support and help for people suffering from malignant diseases, as well as for their families;
- Launching of the first line of psychological support for cancer patients and their families also represents the first psychological helpline in oncology and humane approach in dealing with the psychological, social, spiritual and practical problems of cancer patients, in the manner it has been organized in the developed countries of Europe and the world for decades;
- Launching the first helpline for psychological support is a way of overcoming the problem related to the fact that in Serbia there are few employed psychology experts in everyday oncology practice [6].

METHODS

The SOS phone line for psychological support of cancer patients and their families was based on several basic principles: it was free, anonymous and easily accessible. The broader public was informed of the existence of the phone line through press conferences, guest appearances on popular shows on national television, guest appearances on specialised shows, TV advertisements, articles in daily newspapers and weekly magazines. As promotion material, posters, flyers and brochures were printed and delivered to the general public [6, 7, 8].

The telephone line for the psychological help and support was available from 10 a.m. to 10 p.m., seven days a week and on holidays. Two counseling psychologists were appointed in the morning and two in the afternoon. They were specifically educated on various aspects of malignant diseases, including medical, psychological, social and spiritual consequences of the disease, and also trained on communication skills related to careful listening, emphatic reflection on anything communicated by users, and counselling callers according to their needs. At group meetings held once a week, we provided supervision and discussed what happened during the week (who called, why they called, which problems were the most complex ones and how we could solve them).

According to the Ministry of Health, there are about 50 oncology departments in Serbia, both in large oncology centers and in general hospitals. Only a few, mostly pediatric oncology departments, hire psychologists (majority of them), while departments for adult oncology patients employ neither psychologists nor psychiatrists. In the two comprehensive oncology centers (Institute for Oncology and Radiology of Serbia, Belgrade, and Institute for Oncology of Vojvodina, Sremska Kamenica) there are two psychologists for all the patients, while in other centers consultations with psychiatrists and psychologists are per-

formed only for the most urgent cases, or “when patients make a problem,” which means that the psychosocial support is not easily accessible, and is not a part of the daily oncology practice, as the world and European standards require.

Call logs and data processing

For purposes of the Line, a database was created with a record of each call, as well as the information on the number of calls, first or repeated call, who was making a call (patient, family member, friend, colleague, medical staff), sociodemographic data (gender, age, diagnosis, stage of treatment, place, i.e. area of residence), the description of the problem for which the patient called, check types of psychological, social, spiritual and existential problems as reasons of calling, the types of psychological interventions provided.

Statistical analysis

The data were statistically analyzed using nonparametric statistical procedures (frequencies, percentages).

RESULTS

Out of total number of calls ($n=2,748$), about two thirds were female users and one third were male.

The average age of Line users was 55 (the youngest one was a six-year-old child, and the oldest one was an 88-year-old patient). Most calls were made by persons from Belgrade (63.9%); all other regions were represented in a much lesser extent. Analysis of calls per region demonstrated that there were significantly more calls from some regions (63.9% from Belgrade, 17.8% from Southern Serbia and 11.7% from Central Serbia) than from others (6.2% from Eastern and 7% from Western Serbia), while the least number of calls came from the Republic of Srpska and Kosovo and Metohija (0.1% each).

Significant percentage of callers (28.8%) did not give the information regarding the tumor site, while breast cancer patients (19.7%) and patients with urological malignancies (16.3%) were significantly represented. Majority of callers were oncological patients (66.4%) (1,826 calls in total), followed by their spouses as the so-called “first-line support” (7.7%), and their children (7.3%) (Table 1).

There were also calls we categorized as non-oncological patients (6.1%) (drug addiction, alcohol abuse, suicidal persons, persons with different serious somatic diseases such as hepatitis, AIDS, multiple sclerosis, psychiatric patients, disabled persons, as well as calls regarding family violence and various individual and multiple family psychological problems).

Most (52.4%) conversations were categorized as “psychological support and counseling,” and as continual psychological counseling work (21.1%). Needs for medical in-

Table 1. Demographic and clinical characteristics of Line users (N=2,748)

Characteristics		N (%)
Patient's age (years)	Mean (SD)	55.64 (12.39)*
	Median (range)	58 (6-88)*
Gender of the caller	Female	1755 (63.9)
	Male	993 (36.1)
Geographic area	Belgrade	692 (63.9)
	Republic of Srpska	3 (0.1)
	Central Serbia	321 (11.7)
	Eastern Serbia	171 (6.2)
	Southern Serbia	489 (17.8)
	Western Serbia	192 (7.0)
	Kosovo and Metohija	3 (0.1)
	Vojvodina	538 (19.6)
	Unknown	339 (12.3)
	Tumor site	Breast
Gynecological		194 (7.1)
Lung		152 (5.5)
ORL		82 (3.0)
Genitourinary male		453 (16.5)
Skin and soft tissue		28 (1.0)
Melanoma		36 (1.3)
Thyroid		48 (1.7)
Digestive tract		167 (6.1)
Maxillofacial		24 (0.9)
CNS		36 (1.3)
Hematological		187 (6.8)
Bone		8 (0.3)
Unknown		792 (28.8)
Relationship with the patient	Patient/himself/herself	1826 (66.4)
	Partner	212 (7.7)
	Daughter	140 (5.1)
	Son	60 (2.2)
	Brother	11 (0.4)
	Sister	55 (2.0)
	Colleague	1 (0)
	Neighbor	4 (0.1)
	Doctor	2 (0.1)
	Nurse	1 (0)
	Non-oncological patients	168 (6.1)
	Friend	45 (1.6)
	Cousin	78 (2.8)
	Parents	70 (2.5)
	Other	2 (0.1)
	Unknown	71 (2.6)

* Data are presented as mean value with standard deviation, and median with range.

formation and advice was required by 12.9% of the callers (information regarding the diet while on chemotherapy, information on the skin care following a combined oncological treatment, information on public health services that treat cancer pain, information on blood test results and other diagnostic procedures, information on where mammography can be done, etc.) (Table 2).

Line users mostly called due to the following psychological problems: feeling sad, desperate, helpless, hopeless, feelings of meaninglessness; depressive reaction and demoralization about the positive outcome of the disease;

Table 2. Psychological needs and type of intervention (N=2,748)

Characteristics		N (%)
Repeated call	Yes	1137 (41.4)
	No	1611 (58.6)
	Total	2748 (100.0)
Type of conversation	Psychological counseling	1440 (52.4)
	Medical information	354 (12.9)
	Consultation	18 (0.7)
	Continuous psychological counseling	581 (21.1)
	Provocative indecent calls	35 (1.3)
	Complaint	29 (1.1)
	Recommendation	18 (0.7)
	Rehabilitative and educational	221 (8.0)
	Unknown	52 (1.9)

suicidal thoughts; fears (of being ruined, of pain, disease deterioration, loneliness and being left to themselves); anxiety (feeling worried, uneasy, tense, nervous); mood swings and irritability; family problems (lack of understanding, conflicts, poor communication and relations); feeling rejected in the social and work environment; and the need to be better informed, both quantitatively and qualitatively, on the disease, treatment, adverse side effects of a combined oncological treatment, disease prognosis and treatment outcome.

DISCUSSION

Since an impressive number of calls was noted (2,748 calls over a six-month period), it is obvious that a public, free service for psychology support to cancer patients is needed in Serbia, a country in which psycho-oncology is an underdeveloped area, compared with more developed countries [6, 7]. The largest number of calls was from Belgrade, indicating that the majority of patients from the capital have the availability of information and the awareness of the need for psychological support in situations of crisis and stress, which is the case with the treatment of malignant diseases [8].

The highest percentage of calls was made by patients with breast cancer (19.7%) and patients with urological (16.5%) and digestive system (6.1%) malignancies. We believe that this is the result of the National Campaign against Cancer, which had been conducted in previous years, primarily dedicated to the fight against breast and colon cancer. National Campaign conducted by the Ministry of Health, together with non-governmental associations of patients with breast and colon cancer, resulted in a raised level of awareness of patients in general, as well as in the reduction of stigma and shame to seek psychosocial support.

The majority of callers were cancer patients in various stages of the disease indicating that they find this easily accessible and free service to be needed and useful. Numerous calls by the patients' family members (spouses, children, siblings) indicates that they also suffer due to their family member's illness, since in Serbia there still exists a tradition of family care for the sick member. The

family offers special care in terminal stages of the disease when the patient is literally left to the next of kin, as appropriate units or departments for comprehensive palliative care are not yet sufficiently developed according to existing needs in Serbia.

Unfortunately, further operation of phone lines dedicated to psychological support to cancer patients and their families was not supported by the relevant authorities, who lack any good will to find an acceptable way to continue the work of the first useful service of this kind designed for cancer patients in Serbia.

CONCLUSION

Recognizing the physical, psychological, social, spiritual and existential needs of cancer patients and their families is an important step in the implementation of various psychosocial services for oncology patients during all phases of treatment.

Sensitivity to a variety of psychological problems, which, from the moment of diagnosis of a malignant disease, and then during all phases of an uncertain, long-term oncological treatment cancer patients and their family members are facing, is a prerequisite to any kind of psychosocial interventions implemented in oncology practice. Without this prerequisite, the basic postulates (bio-psycho-social model, holistic approach and empathic attitude toward the most difficult patients) are neglected, thus undermining the basis of modern oncological approach. The overall

objective of launching free of charge SOS telephone line was providing professional psychological support and assistance to cancer patients in all stages of the disease and treatment, as well as to their family members, keeping in mind several important facts: firstly, a malignant disease has a specific "background" and brings with it special psychological weight; secondly, a malignant disease of a family member is a powerful source of stress and crisis for the entire family; and thirdly, in Serbia, cancer patients from all over the country and in all cancer centers usually do not have the opportunity to receive face-to-face professional counseling and support if they need it during different phases of oncology treatment. Providing psychological support by telephone is a useful and necessary free of charge service for cancer patients and their families in Serbia.

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NOTE

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Прва телефонска линија за пружање психолошке подршке онколошким болесницима и њиховим породицама у Србији

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КРАТАК САДРЖАЈ

Увод У октобру 2010. године Српска асоцијација за психоонкологију, у сарадњи са Министарством здравља Републике Србије и Републичким заводом за здравствено осигурање, покренула је први Национални телефон за бесплатну психолошку помоћ и подршку онколошким болесницима и њиховим породицама.

Циљ рада Циљ овог рада био је да се прикажу резултати рада првог националног телефона за психолошку подршку особама с онколошким обољењима и члановима њихових породица.

Методе рада Телефон за пружање психолошке помоћи и подршке био је доступан свих седам дана у недељи и празницима од 10 сати ујутру до 10 сати увече. Било је едуковано 12 психолога, по два саветника-психолога била су ангажована пре подне и после подне. Једном недељно смо на групним састанцима размењивали информације о свему што се током недеље дешавало (ко се јавља, зашто се јавља, који су проблеми најсложенији и како их превазићи). Основ-

ни принципи рада Линије су: анонимност за кориснике (ако то желе), бесплатна услуга, доступност корисницима из целе Србије, пажљиво слушање, емпатично рефлектовање свих садржаја које корисници износе и адекватно саветовање.

Резултати Од почетка до краја пројекта (октобар 2010 – април 2011) било је укупно 2.748 позива из целе Србије. Више од половине позива били су поновљени позиви, јер су пацијенти имали потребу за континуираним психолошким саветовањем. Већином су се јављале жене (63,9%) у поређењу с мушкарцима (35,4%) који су користили Линију. Већина разговора је категорисана као „психолошка подршка и саветовање“ (52,4%) и као континуиран психолошки саветодавни рад (21,1%).

Закључак Велики број позива указује на то да је овакав начин јавног, бесплатног сервиса потребан за пружање психосоцијалне помоћи и психолошке подршке онколошким болесницима.

Кључне речи: психосоцијална подршка; психосоцијални аспекти; онкологија

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