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ORIGINAL ARTICLE

The need for support among cancer patients – a preliminary study

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Summary

Purpose: *To analyze the demand for support among cancer patients subjected to systemic treatment or radiotherapy.*

Methods: *The study included 321 cancer patients treated in three Polish oncology centers. More than 73% of the responders were diagnosed with cancer not earlier than a year prior to the study. Most of the patients received chemotherapy (74.8%); nearly a half of the subjects (46.7%) were subjected to radiotherapy and every tenth person received hormonal therapy. The subjects were examined with the Berlin Social Support Scales (BSSS).*

Results: *Emotional and informative support were the most frequently needed forms of support. Age and sex did not exert significant effect on the need for support and the level of received support. Individuals with higher education showed the lowest scores of support seeking. The availability of instrumental support displayed the lowest score, especially among the individuals treated at daily chemotherapy units. The type of oncological treatment did not change the patients' perception of support.*

Conclusions: *Irrespective of their demographic and clinical characteristics, cancer patients should be provided with emotional, informative and instrumental support.*

Key words: *cancer, oncology, psycho-oncology, support*

Introduction

Diagnosis of cancer raises anxiety and concerns [1,2]. It puts patients in a difficult, previously unknown situation, and necessitates changes in previous life status. Another issue is the social perception of cancer as a devastating condition associated with poor prognosis. Despite clinical evidence that an early diagnosed cancer can be fully curable, it is still mostly perceived in the context of burdensome anticancer therapy, its adverse events or harmful surgical procedures [3,4]. This, at least in part, results from a "military" language used in the context of a neoplastic disease e.g. "to fight cancer", "to be defeated by cancer", "aggressive treatment", etc.

Emotions experienced by cancer patients during the consecutive stages of treatment and recovery may either improve their quality of life or markedly deteriorate their health status. This necessitates holistic approach towards a patient, i.e. extension of treatment on biopsychosocial, spiritual and cultural dimensions. An important component of the holistic approach is support from close relatives, medical staff and other supportive sources. Equally important are the appropriate recognition of the patients' needs and patient readiness to receive support [5].

The aim of this study was to analyze the demand for support among cancer patients subjected

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to systemic treatment or radiotherapy. We formulated the following research questions: 1) What are the demands of cancer patients for emotional, spiritual, informative, instrumental and material support? 2) Do sex, age and educational level of cancer patients determine the subjective levels of perceived, needed and received support? 3) Do the type of anticancer treatment, its duration and setting exert any effect on the need for support, support seeking and satisfaction with support? 4) Who constitutes the main source of support for cancer patients?

Methods

This study included 321 cancer patients treated in three Polish oncology centers, in Cracow, Brzozow and Orzechowka. Participation in the study was voluntary and anonymous. Sociodemographic characteristics of the participants are presented in Table 1. The majority of the patients were women (67.3%), individuals older than 40 years (nearly 90%), married (81.0%), with secondary or vocational education (more than 70%). Only 28.1% of the responders were still professionally active; the remaining 59.8% received medical pension or were retired. Clinical characteristics of the study participants are summarized in Table 2. Most of the patients received chemotherapy (74.8%); nearly a half of the subjects (46.7%) were subjected to radiotherapy and every tenth person received hormonal therapy. The vast majority of the study participants (90.3%) were individuals with no previous history of anticancer treatment. More than 73% of the respondents were diagnosed with cancer not earlier than a year prior to the study. Nearly a half of the participants were treated in a hospital setting, one third at a daily chemotherapy unit, and 15.6% at a radiotherapy department.

Our team created a special questionnaire adapted solely to the purpose of the study, and all participants completed it which included questions on patient demographics, clinical status, opinions of expected and received support, and its sources (Figure 1).

Moreover, the participants were examined with the BSSS [6]. These are self-reported measures to assess cognitive and behavioral dimensions of social support. BSSS is comprised of 8 scales, each containing several subscales. Responders rate their agreement with the scale statements on a 4-item scale, from 1 (strongly disagree) to 4 (strongly agree). The scores were obtained by generating the scale mean scores.

Statistics

The results were subjected to statistical analysis with IBM SPSS package. The intergroup comparisons were based on the Student t-test, one-way analysis of variance (ANOVA) and chi-square test. The results of all the tests were considered significant at $p<0.05$.

Table 1. Demographic characteristics of the study participants (N=321)

Characteristics	*N*	*%*
Oncology center		
Brzozow	127	39.6
Cracow	158	49.2
Orzechowka	36	11.2
Age, years (range)		
19-39	33	10.3
40-54	85	26.5
55-59	60	18.7
60-64	65	20.2
65+	78	24.3
Sex		
Women	216	67.3
Men	105	32.7
Marital status		
Married	252	78.5
Single	25	7.8
Widowed	31	9.7
Divorced	3	0.9
Missing data	10	3.1
Education		
Primary	32	10.0
Vocational	93	29.0
Secondary	140	43.6
Higher	56	17.4
Occupational status		
Full-time employee	75	23.4
Part-time employee	15	4.7
Contract employee	4	1.2
Pensioner	192	59.8
Student	4	1.2
Unemployed	11	3.4
Never worked	8	2.5
Other	12	3.7

Table 2. Clinical characteristics of the study participants (N=321)

Characteristics	*N*	*%*
Type of treatment		
Chemotherapy	240	74.8
Radiotherapy	150	46.7
Hormonal therapy	34	10.6
Other	2	0.6
Missing information	0	0.0
Duration of treatment		
1-3 months	120	37.4
4-12 months	116	36.1
1-2 years	35	10.9
2-5 years	40	12.5
Missing information	10	3.1
Treatment setting		
Hospital ward	157	48.9
Daily chemotherapy unit	104	32.4
Radiotherapy department	50	15.6
Other	10	3.1
History of cancer		
No	290	90.3
Yes	31	9.7

Year of birth: ☐☐☐☐

Sex:

- ☐ woman
- ☐ men

Marital status:

- ☐ married
- ☐ single
- ☐ widowed
- ☐ common law
- ☐ other (please specify): _____

Education:

- ☐ primary
- ☐ vocational
- ☐ secondary
- ☐ higher

Place of residence

- ☐ small town (up to 100 000)
- ☐ big city (100 000 and above)
- ☐ village

1. *What is your occupational status:

- ☐ full-time employee
- ☐ part-time employee
- ☐ contract employee
- ☐ disability pensioner
- ☐ retired
- ☐ student
- ☐ unemployed with unemployment benefits
- ☐ I have never been working
- ☐ other (please specify): _____

2. Have you ever been operated on for your cancer?

- ☐ Yes – please, specify type of the procedure: _____
- ☐ No

3.* What anticancer treatment you currently receive?

- ☐ Chemotherapy
- ☐ Radiotherapy
- ☐ Hormonal therapy
- ☐ Other (please specify): _____

* Select all answers that apply; otherwise, choose only one.

Continued on the next page

4. Duration of the therapy:

- ☐ 1 to 3 months
- ☐ 4 to 12 months
- ☐ 1 to 2 years
- ☐ 2 to 5 years

5. Where do you receive your treatment?

- ☐ inpatient setting
- ☐ outpatient setting (e.g. outpatient chemotherapy unit)
- ☐ outpatient radiotherapy unit

6. Is this the first time you have been diagnosed with a cancer?

- ☐ Yes
- ☐ No – please, specify the number of previous diagnoses: _____

7. What is support? Please define: _____

_____

_____

8.* Who is the principal source of the support you receive?

- ☐ Spouse
- ☐ Children
- ☐ Siblings
- ☐ Parents
- ☐ Distant relatives
- ☐ Nurses
- ☐ Physicians
- ☐ Volunteers
- ☐ Others (please specify): _____

9. * What types of support you receive most often?

- ☐ Emotional support (understanding, expression of empathy and caring)
- ☐ Informational support (information on treatment, rehabilitation and self-care)
- ☐ Instrumental support (instruction, demonstration, medical advice, modeling of health behaviors)
- ☐ Material support (material and financial support, medications)
- ☐ Spiritual support
- ☐ I do not receive any support (none of the above)

10. * What is the type of support you expect most?

- ☐ Emotional support (understanding, expression of empathy and caring)
- ☐ Informational support (information on treatment, rehabilitation and self-care)
- ☐ Instrumental support (instruction, demonstration medical advice, modeling of health behaviors)
- ☐ Material support (material and financial support, medications)
- ☐ Spiritual support

Figure 1. Questionnaire used during this study.

Table 3. Types of support expected by the study participants (%)

What type of support do you expect?	*Total*	*Age (years)*					*Gender*
		19-39	*40-54*	*55-59*	*60-64*	*65+*	*F*
Emotional support (understanding, assistance, sympathy)	58.6	69.7	56.5	60.0	60.0	53.8	63.0
Informative support (information required for treatment, rehabilitation and self-care)	52.0	48.5	47.1	50.0	55.4	57.7	50.5
Instrumental support (training, counselling, modulation of health-seeking behaviors)	15.6	21.2	21.2	6.7	20.0	10.3	15.7
Material support (financial support, provision of medications)	20.6	18.2	17.6	25.0	20.0	21.8	19.4
Spiritual support	31.5	24.2	29.4	31.7	41.5	28.2	32.9
Missing information	5.0	6.1	4.7	6.7	3.1	5.1	5.6
Total (N)	321	33	85	60	65	78	216

F: females

Table 4. Mean BSSS scores in the study group

Parameter	*Mean*	*N*	*Min*	*Max*	*SD*
BSSS – Perceived support (emotional)	3.59	321	1.00	4.00	0.56
BSSS – Perceived support (instrumental)	3.69	321	1.00	4.00	0.54
BSSS – Need for support	3.09	321	1.00	4.00	0.60
BSSS – Support seeking	3.12	321	1.00	4.00	0.80
BSSS – Received support (emotional)	3.57	321	1.22	4.00	0.56
BSSS – Received support (informative)	3.53	321	1.00	4.00	0.71
BSSS – Received support (instrumental)	3.69	321	1.00	4.00	0.53
BSSS – Overall satisfaction with support	3.79	321	1.00	4.00	0.55

SD: standard deviation

Table 5. Mean need for support and support seeking scores depending on educational level of the study participants

Parameter	*Educational level*		
	Primary	*Vocational*	*Secondary*
BSSS – Need for support	3.06	3.24	3.08
BSSS – Support seeking	3.16	3.28	3.18
Total (N)	32	93	140

Results

Concerning the type of support they expected, cancer patients usually pointed to emotional support (understanding, assistance, sympathy). The need for this type of support was declared by 58.6% of the responders; this made emotional support the most demanded type of support in all age categories except the oldest individuals who pointed to informative support slightly more often. Nevertheless, the age-specific differences in the need for emotional support did not prove significant on statistical analysis. Women declared this need significantly more often than men (63 vs 49.5%, p=0.022). Informative support was another important type of support expected from the patients. The need for this type of support was declared by more than half of the responders (52%), and the demand for it did not differ significantly across the age categories. Furthermore, although declared slightly more often by men, this difference proved statistically insignificant. Spiritual support was the third most often declared type of needed support, expected by one third of responders (31.5%). In contrast, our patients less often claimed on the need for material (20.6%) and instrumental support (15.6%). Although we did not find age- or sex-specific differences in the demand

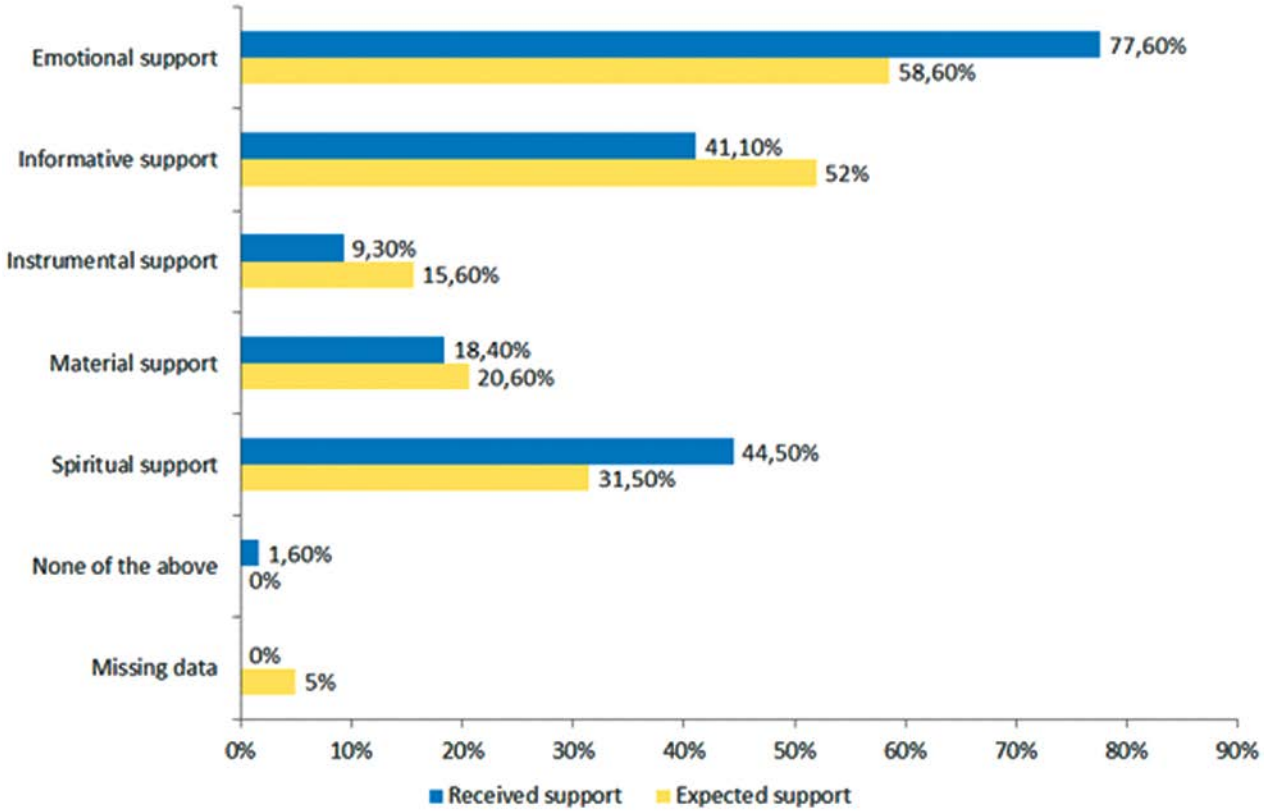

Figure 2. Levels of support expected and received by the study participants.

Table 6. Relationship between support expected and received by the study participants

Parameter	*Expected and received* %	*Received albeit unexpected* %	*Non-received albeit expected* %	*Unexpected and non-received* %	*Total N*
Emotional support	53.6	24.0	5.0	17.4	321
Informative support	29.6	11.5	22.4	36.4	321
Instrumental support	6.9	2.5	8.7	81.9	321
Material support	10.6	7.8	10.0	71.7	321
Spiritual support	24.6	19.9	6.9	48.6	321

for these types of support, compared to the remaining subjects, individuals aged 55 to 59 and older than 65 years declared the need for instrumental support slightly less and slightly more often, respectively (Table 3).

Our patients declared high levels of overall satisfaction with social support (mean 3.79 on a scale from 1 to 4). Moreover, relatively high scores were documented for perceived and received instrumental support (both equal 3.69). In turn, our participants claimed lower levels of support seeking (3.12) and need for support (3.09) (Table 4). Male and female patients did not differ in terms of their BSSS scores. The only exception pertained was in support seeking scores, as women appeared with a relatively higher score than men (3.18 vs 3.00); however, this sex-specific difference did not reach statistical significance (p=0.053). Similar to sex, we did not document significant effects of age on BSSS scores. Although the result of ANOVA pointed to potential age-related differences in the level of support seeking (p=0.048), eventually this was not found on *post-hoc* testing. Therefore, it can be concluded that neither sex nor age exerted significant effects on subjective need for support and received support levels. Support seeking was the only variable the levels of which may differ between women and men or among individuals belonging in various age categories, but this issue needs to be investigated in further researches.

While educational level did not modulate perceived and received support scores, it exerted significant effect on the levels of need for support and support seeking. Subjects with higher education showed significantly lower need for support scores than did subjects with vocational education

Table 7. Received support depending on a treatment setting

Received support	*Total*	*Hospital ward*	*Daily chemotherapy unit*	*Radiotherapy unit*	*Other*
	%	%	%	%	%
Emotional support	77.6	73.9	86.5	76.0	50.0
Informative support	41.1	39.5	38.5	52.0	40.0
Instrumental support	9.3	10.8	1.0	24.0	0.0
Material support	18.4	18.5	19.2	20.0	0.0
Spiritual support	44.5	47.8	43.3	38.0	40.0
None of the above	1.6	1.9	1.0	0.0	10.0
Total (N)	321	157	104	50	10

(p=0.008). Moreover, patients with higher education showed significantly lower levels of support seeking (p<0.001; Table 5).

Receiving radiotherapy or chemotherapy did not exert significant effect on the need for support, perceived support and received support scores. The differences between the BSSS scores of patients who were subjected to radiotherapy and those who were not was not statistically significant, similar to individuals receiving and non-receiving chemotherapy. The BSSS scores were also not changed by the duration of anticancer treatment. We analyzed the subsets of patients treated for 1-3 months, 4-12 months, 1-2 years and 2-5 years. These groups did not differ significantly in terms of their mean BSSS scores. Moreover, we did not find a statistically significant relationship between mean BSSS scores of subjects treated in an inpatient or outpatient setting.

Subsequently, we analyzed the relationships between the levels of received support and the need for support in order to identify potential deficits in this matter. Apart from the determination of BSSS scores, we asked two additional multiple-choice questions referring to the types of received and needed support: "What is the main kind of support you receive?" and "What kind of support do you expect?". The relationship between types of needed and received support is presented on Figure 2. Most of the responders (77.6%) declared that they received emotional support. A kind of excessive emotional support as the need for this type of support was declared by a lower number of responders (56.8%). A similar phenomenon of excessive support was observed in the case of spiritual support. In contrast, an evident "deficit" of informative support was registered, expected by 52% of the responders and received only by 41.1%. A more comprehensive analysis of the answers to the above-mentioned questions was conducted and identified patients who both expected and received a given kind of support, individuals who did not receive it despite their expectations or received an unexpected kind of support, and those who neither expected nor received a certain kind of support. The distribution of our patients to these four groups is presented in Table 6. The degree of the "deficit" turned out to be the largest in the case of informative support: we identified as many as 22.4% of the responders who had declared the need for this type of support but did not receive it. The subjectively perceived support differed, depending on the treatment setting. Patients treated at outpatient chemotherapy units declared receiving emotional support significantly more often than did the subjects treated in a hospital setting or at radiotherapy units (p=0.046). In contrast, patients of radiotherapy units claimed that they received instrumental support significantly more often than did the others (p<0.001). The subjectively perceived availability of instrumental support was the lowest among patients treated at daily chemotherapy units (Table 7).

Finally, patients were asked about the main sources of their support. As the availability of support from close relatives turned out to be associated with the family status of the responders, the distribution of answers to this question was analyzed in the whole group and for married individuals separately, since they formed the largest fraction of our participants. As most of the study subjects belonged to older age categories, it is not surprising that most of them pointed to their spouse and children as the main sources of their support. The third most frequently declared source of the support were nurses (37.7%), followed by patients' siblings (35.5%) and physicians (34.5%). A relatively low fraction of patients who pointed to their parents as the source of support likely reflects the age structure of the study group, predominated by individuals older than 50 years.

Discussion

Neoplastic disease exerts negative effects on the well-being of most cancer patients as it affects

their most precious values, namely health and life [5]. Side effects of anticancer treatment and development of undesired symptoms determine multidimensional changes in both the somatic and psychosocial sphere, and overall functioning of oncological patients, being in particular need for support and assistance [7]. Due to its complex functional and structural character, the definitions of support used in various studies may vary considerably; nevertheless, the support is typically defined as a kind of social interaction undertaken by one or more individuals involved in a problematic, difficult, stressful or traumatic situation [1]. According to Franks et al. [8], support constitutes a system of social relationship, exerting direct or indirect positive effect on an individual. The support is often postulated to be an important protective factor, as it exerts significant positive effect on the functioning of a patient, both at a family and social level, and attenuates the severity of negative symptoms, such as anxiety and depression [9]. Our patients presented with high levels of satisfaction with social support, and were satisfied with both received and perceived instrumental support. Similar results were reported previously by Kieszkowska-Grudny et al. [10] who studied a group of cervical cancer patients. Women subjected to anticancer treatment reported significantly higher levels of virtually all types of social support than did the group of healthy controls; moreover, the authors identified age as a significant determinant of support seeking [10].

Both women and men participating in our study showed relatively high levels of satisfaction with their experienced support. The only considerable sex-specific difference pertained to support seeking was that women sought support more often than men and this difference was statistically significant ($p<0.05$). According to Norcross et al. [11], women use a greater number of active interpersonal relationship-based forms of coping with the disease and are more prone to seeking and utilizing social support in a difficult situation. Exchanging information and advice may promote better understanding of one's situation and attenuate the ailments associated with anticancer treatment. This concept is supported by the results published by Schroevers et al. [12] who studied a group of patients diagnosed with cancer; the presence of depressive symptoms was determined by low level or lack of support. Lack of support and loneliness of patients are reflected by deterioration of their well-being and higher mortality rates [13].

The present study revealed that responders with higher education showed lower levels of need for support and support seeking compared with those with other educational levels. This may reflect greater independence of the former group, as higher education is usually associated with higher levels of information seeking and problem solving skills.

Social support is particularly helpful at the time of diagnosis and treatment of neoplastic disease [14]. Patients who receive support show greater adherence to anticancer therapy and involve in a therapeutic process to a larger extent [3,9,15]. Availability of friendly and helpful persons provides them with the feeling of safety and acceptance, and attenuates anxiety and helplessness. Due to emotional support, suffering individuals can be freed from their tensions and negative emotions; they may express their fears and concerns, display their sadness and gain the sense of hope [7]. One of the first studies dealing with social interactions showed that emotional support, usually obtained from close relatives, results in lower levels of distress and depression, and can be helpful in the psychosocial adjustment to neoplastic disease [10,11].

This study showed that most of the patients received support from their spouses, siblings and, interestingly, medical personnel: nurses and physicians. It is noteworthy that responders obtained more emotional and spiritual support than expected. According to Hulahan and Moss, close relatives who take care for patients and witness their suffering can experience similar negative emotions as the affected family member [16]. A meta-analysis conducted by Duric and Stockler revealed that women who declare greater availability of family support show more positive attitude to systemic treatment [17]. Multimodal anticancer treatment in a hospital setting, especially surgery and adjuvant chemotherapy and/or radiotherapy, raises strong concerns, not only to patients but also among their close relatives. Thus, our finding on the excessive support likely reflects strong bonds in the families of our participants. However, the fact that cancer patients participating in this study showed low levels of both needed and received instrumental support is alarming and requires further research.

To summarize, emotional support (58.6%) and informative support (52%) are most frequently needed forms of support among cancer patients. Age and sex of cancer patients do not exert significant effect on the need for support and the level of received support. Individuals with higher education present the lowest scores of support seeking. The availability of instrumental support is the lowest scored; patients of radiotherapy units

receive higher levels of this support than individuals treated at daily chemotherapy units. The type of oncological treatment does not change patients' perception of support. Cancer patients receive more emotional and spiritual support than they expect. In contrast, they suffer from a deficit of informative support.

Support is a specific form of help pertaining to the ability to stimulate and maintain one's self-confidence, activity and psychophysical capabilities. Medical personnel working at oncology departments not only play an important role in the identification of psychosocial dysfunction related to therapeutic process and the disease itself, but also participate in the diagnosis and prevention, providing necessary information and basic emotional and informative support for patients and their relatives. Additional psychosocial support should be offered to the patients presenting with depression, grief and existential suffering, who neither seek nor obtain enough help. Consequently the degree of support deficit and the level of perceived social support should be determined possibly early, in order to implement appropriate psychotherapeutic measures. The range of available support should be classified according to its type (contents) and function in human interactions. The results of this study may be useful in the diagnosis of needs and problems related to expected, obtained and perceived support. Moreover, they may be considered during planning and execution of oncological care.

Conflict of interests

The authors declare no confict of interests.

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