

ORIGINAL ARTICLE

Attitudes of cancer patients after diagnosis: How cancer affects social life? A Turkish Oncology Group study

Erdinc Nayir¹, Mahmut Bakir Koyuncu², Ece Esin³, Ibrahim Turker⁴, Ozgur Tanriverdi⁵, Mukremin Uysal⁶, Ozlem Er⁷, Atakan Demir⁸, Tulay Tuzel Akman⁹, Kezban Nur Pilanci¹⁰, Semra Paydas¹¹, Muharrem Kocar¹², Pinar Saip¹³, Saadettin Kilickap³, Serdar Turhal¹⁴, Turgut Kacan¹⁵

¹Department of Medical Oncology, Kahramanmaraş Necip Fazil City Hospital, Kahramanmaraş; ²Department of Internal Medicine, Mersin University Faculty of Medicine, Mersin; ³Department of Medical Oncology, Hacettepe University Faculty of Medicine, Ankara; ⁴Department of Medical Oncology, Oncology Training and Research Hospital, Ankara; ⁵Department of Medical Oncology, Mugla University Faculty of Medicine, Mugla; ⁶Department of Medical Oncology, Afyon University Faculty of Medicine, Afyon; ⁷Department of Medical Oncology, Acibadem Maslak Hospital, Istanbul, Turkey; ⁸Department of Medical Oncology, Cerrahpasa University Faculty of Medicine, Istanbul; ⁹Department of Medical Oncology, Izmir Tepecik Training and Research Hospital, Izmir; ¹⁰Department of Medical Oncology, Haseki Training and Research Hospital, Istanbul; ¹¹Department of Medical Oncology, Cukurova University Faculty of Medicine, Adana; ¹²Department of Medical Oncology, Sanliurfa Training and Research Hospital, Sanliurfa; ¹³Department of Medical Oncology, Istanbul University Oncology Institute, Istanbul; ¹⁴Department of Medical Oncology, Anadolu Medical Center, Istanbul; ¹⁵Department of Medical Oncology, Afyon State Hospital, Afyon, Turkey

Summary

Purpose: Each year, 12.7 million people learn that they have cancer and 8.2 million people die of= cancer worldwide. Cancer is a major public health issue which causes fundamental changes in the lives of patients and their families. The purpose of this study was to evaluate the lives of patients after diagnosis and determine the changes in their lifestyles.

Methods: Between September 2013 to December 2013, a questionnaire consisting of 22 questions was administered during a face to face interview to patients at 13 different Oncology Units in Turkey. Each patient was queried during the administration of his/her chemotherapy. Eight of the questions featured independent choices, and 14 had dependent (multiple) choices.

Results: A total of 1300 patients were included in the study.

Of patients 9.5% were 71 years of age and older which was the oldest age group. The mean patient age was 54.6±13.8 years. Of the whole group of patients 58.5% were female and 41.5% male. After diagnosis, 64% of the patients reported that they were complying with guidelines for a healthy lifestyle and 80% said that they were eating healthier food. At the time they filled in the questionnaire, more than half of the patients (57.3%) felt optimistic about their disease.

Conclusions: Diagnosis of cancer may change the patients' dietary and reading habits, social relationships, activities and more importantly, their point of life view.

Key words: cancer, chemotherapy, lifestyle, media, psychological status

Introduction

Each year, 12.7 million people learn that they have cancer and 8.2 million people die from cancer worldwide [1]. According to 2011 data from the Turkish Ministry of Health, the incidence of

cancer is 281 per 100,000 citizens, per year. This means that one out of 350 people in Turkey is diagnosed with cancer per year [2]. If preventive measures are not taken, it is estimated that the cancer

burden of the world in general will increase and there will be 24 million newly diagnosed cancer cases in 2030, and deaths from cancer will reach 17 million [3].

We know that most of the patients with newly diagnosed with cancer and their relatives are inclined to change their lifestyles and daily habits. When they hear the word “cancer”, they start searching about lifestyle changes and thinking about what can be done in addition to the medical treatments. According to our observations, their social behaviors and activities start changing also. Some of them suddenly become depressed and limit their social life. On the other hand, some others become more optimistic and more socialized and start thinking “what can I do myself during the course of the disease?” and “I have to spend the rest of my life tremendously”. There have been claims that changes toward a healthier lifestyle are related to improved treatment outcomes in cancer patients [4,5].

For this reason, we wanted to determine the changes in lifestyle behaviors and practices in cancer patients after the diagnosis and designed a questionnaire to clarify their attitudes.

Methods

Between September 2013 to December 2013, a questionnaire consisting of 22 questions was administered during a face to face interview to 1300 patients at 13 different Oncology Units in Turkey (Table 1). Each patient was queried during the administration of his/her chemotherapy. Eight of the questions featured independent choices, and 14 had dependent (multiple) choices.

Statistics

All data was analyzed using the Statistical Program for Social Sciences (SPSS) version 14.0 software program (SPSS Inc., Chicago, Ill). Study data were presented with descriptive statistics (e.g., mean, median, standard deviation, range, number, percentage). Quantitative and qualitative data were compared with t-test and chi-square test, respectively. Statistical level of significance was accepted as $p < 0.05$.

Results

A total of 1300 patients were included in the study. Of the patients, 9.5% were 71 years old and over, which was the oldest age group. The patient mean age was 54.6 ± 13.8 years. Of the whole patients 58.5% were female and 41.5% male. Most of the patients were married (84.2%) and living with

their families (92.2%). Approximately one-third of the patients had breast cancer which was the most frequently seen cancer in this study. Most of the patients had children at the time of the study. Of the patients, 60% had an elementary school education or less. Some of the patient socio-demographic characteristics are summarized in Table 2.

Fifty-two percent of the female patients and 61% of the males were at advanced stage (stage 4 or 5). Twenty percent of the individuals at advanced stage said that people they frequently used to see decreased. On the other hand, this proportion was much less (about 5%) in individuals at earlier stages and this difference was statistically significant ($p < 0.05$).

Of the patients, 51% had no regular reading habits before and after diagnosis, and 17.3% said that they started reading subjects about health-diseases. Only 11.8% of the patients noted that they started watching movies about health-diseases issues, while 70% did not change their reading habits and movies they watch after diagnosis. In older age groups, more than half of the patients said that they did not read regularly.

When it comes at chats about their diseases, 50% of them answered that they started with their current treatments and side effects. Approximately half of the patients noted that groups of people they frequently used to see increased in quantity after the time of diagnosis and the subjects they talked about did not change.

When we specifically asked whether the patient had healthier dietary habits after the diagnosis or not, 81% of the respondents answered “Yes”. The answers were much the same in all age groups. A 64.8% of the patients pointed that they started practising healthy living recommendations such as regular exercise and smoking cessation after the time of diagnosis. However, 47% of the patients in the oldest age group (71 years of age and older) said that they did not follow healthy lifestyle recommendations even after diagnosis. More than half of the patients (56.2%) noted that their sympathy and support for charity campaigns increased after diagnosis.

Patients were asked what kind of statements best described their response to the diseases they had and treatments administered to evaluate how they coped with the disease. The answers included “I think I am losing my control”, “I started to feel the meaning of life”, “I started to ask myself: Why me?” and “I feel stronger than before”. Forty-one percent of the patients said that they started to feel the meaning of life, 16.4% noted that they felt stronger than before. This means that more than

Table 1. Journey of cancer: Changes in patient's life after diagnosis, how the process started and how it continues

Survey No:

Diagnosis:

Stage:

Stage I

Your age: Your gender: Female Male Marital status: Single Single and I am responsible for looking after a person / persons Married Education: No Education Primary / Secondary School High School Bachelor Degree Postgraduate
--

Stage II

1) The books I read after the diagnosis of my disease... a) Started to become about the subjects of health-diseases. b) Started to become time-killing, entertaining, resting. c) I kept my previous habits. d) I chose from the books which I delayed for later. e) I do not read regularly.
--

2) The movies I watch after the diagnosis of my disease... a) Started to become about the subjects of health-diseases. b) Started to become time-killing, entertaining, resting. c) I kept my previous habits. d) I chose from the movies which I delayed for later. e) I do not regularly watch movies.

3) When it comes to your disease during a chat, what is your starting point at it? a) My current treatment. b) Side effects of my treatments. c) The reason for cancer and how my first diagnosis was made. d) My doctor's opinions about the course of the disease. e) I express my unwillingness to talk about this subject. f) Other.....
--

4) After my disease was diagnosed: (Check one selection from both categories) I - Group of people I frequently see; a) Increased in quantity (My acquaintances more frequently concern about me). b) No changes in quantity. c) Decreased in quantity (I realized that some of my former acquaintances do see me any more). II - The subjects you are talking about d) Got deeper- We started to pour out more than in the past. e) No changes. f) Got more superficial - We were unable to pour out as much as in the past.
--

5) I started to care about whether my food was healthy or not rather than its taste, after the diagnosis of my disease. a) Yes. b) No. c) Your additional input:

6) I started practicing healthy living recommendations such as regular exercising and quitting smoking, after the diagnosis of my disease. a) Yes. b) No. c) Your additional input:
--

7) My sympathy and support for charity campaigns increased after the diagnosis of my disease. a) Yes. b) No. c) Your additional input:

Continued in the next page

8) After the diagnosis of my disease: (You may check more than one selection)

a) I felt like I lost control over my life.
 b) I began to feel the meaning of my life.
 c) I started questioning; "Why me?".
 d) I began to feel stronger.
 e) Your additional input:

9) I started to experience difficulties in expressing myself in various environments, which I never experienced before, after the diagnosis of my disease.

a) Yes.
 b) No.
 c) Your additional input.....

10) To what extent do the side effects of your current method of treatment affect your life?

a) They affect extremely negatively - I cannot ignore them.
 b) They affect very negatively - I can rarely ignore them.
 c) They affect negatively- I can frequently ignore them.
 d) No negative effects at all- I can completely ignore them.

11) After your disease was diagnosed;

a) The number of my live-in travels/expeditions decreased.
 b) The number of my live-in travels/expeditions increased.
 c) The number of my live-in travels/expeditions did not change.

12) The number of your daily travels/expeditions after your disease was diagnosed;

Decreased Increased Did not change

13) My interest in current media (Daily newspapers, Magazines, TV News) after diagnosis of my disease;

Decreased Increased Did not change

14) What is the closest to your mood currently?
 (You may check more than one)

a) I feel strong.
 b) I feel weak.
 c) I feel hindered and angry.
 d) I think I am hopeless and pessimistic.
 e) I feel I am hopeful and optimistic.
 f) I feel confused.

half of the patients (57.3%) felt optimistic about their disease. The answers were similar in all age groups. Thirty-four percent of the patients declared that treatment side effects had no negative effects at all and noted that they could completely ignore them.

Patients were also asked whether they started experiencing difficulties about expressing themselves in various environments, which they never experienced before, after the diagnosis of their disease or not; 70% of them answered "No".

Patients were asked about travelling after the diagnosis and 48.8% of them said that their travelling activities decreased because of the disease and treatment procedures. On the other hand, 13.1% of the patients said that they were travelling more than before. The answers were similar to the question about daily excursions.

Participants were asked about their interest in daily news. More than half of the patients (57%) said that their interest in daily news by the media did not change after diagnosis.

Table 2. Patient socio-demographic characteristics

<i>Characteristics</i>	<i>N</i>	<i>%</i>
Gender		
Male	540	41.5
Female	760	58.5
Level of education		
Not educated	121	9.3
Primary-secondary school	655	50.4
High school	298	22.9
Undergraduate student	177	13.6
Postgraduate student	49	3.8
Marital status		
Single	205	15.8
Married	1095	84.2
Diagnosis		
Breast cancer	386	29.7
Colorectal cancer	240	18.5
Genitourinary cancer	171	13.2
Lung cancer	145	11.2
Stomach cancer	76	5.8
Others	282	21.6
Total	1300	100

In the final part of the questionnaire, patients were asked about their current feelings. Of them, 25.6% noted that they felt stronger than before, 20.8% stated that they felt hopeful and optimistic. About one quarter of the patients felt hindered, angry, hopeless and pessimistic about their disease and 27.9% said that they felt confused after diagnosis. In the 21-30 years age group, no participant answered that he/she felt weak. Some of the patient attitude changes are summarized in Table 3.

Discussion

In this study, about 70% of the patients did not change their reading habits and movies they watched after diagnosis and, especially in older age groups, more than half of the patients said that they did not read regularly. We could not find any data about the reading habits of cancer patients but it can be said that Turkish cancer patients read less than the general population. This difference might be due to the fact that 60% of the patients in this study had only an elementary school education or less.

About half of the patients said that people they frequently used to see increased but the subjects they talked about did not change. Generally, Turkish cancer patients tend to be friends with each other during their chemotherapy. Despite the extended social relationships, they keep up talking about non-illness issues. This might explain the high positivity of them during treatments. Cultural practices and beliefs about cancer is also an important issue. Culture influences individuals' perception of health, expectations for care, treatment choices, advanced healthcare planning and other aspects of care. In many Middle East countries, cancer related myths and stigma about cancer are important problems that must be addressed. Cancer symptoms or body parts affected by the disease can create stigmata. Patients with gynecological or breast cancer often express a feeling of isolation. In addition, some of the family members can alternatively be a source of stigmata and they try to isolate the patient. On the other hand, most of the patients who have a family with strong relationships are more likely to cope with cancer. In addition, many individuals rely on their spirituality and faith when coping with illness in Middle East countries. They may experience positive outcomes like less depression, delayed onset and slower progression of physical disability. In conclusion, it can be said that culture and family

Table 3. Some of the attitude changes of the patients

	N	%
Preferences for healthier food after diagnosis		
Yes	1051	80.8
No	249	19.2
Change to a healthier lifestyle after diagnosis		
Yes	842	64.8
No	452	34.8
Preferences to contribute more to charity campaigns		
Yes	730	56.2
No	566	43.5
Difficulties in expressing themselves		
Yes	385	29.6
No	913	70
Number of travels after diagnosis		
Decreased	635	48.8
Increased	170	13.1
No change	495	38.1
Interest in current media after diagnosis		
Decreased	231	17.8
Increased	322	24.8
No change	747	57.5

can affect the individual both in positive and negative ways [6].

We think one of the most striking points of this study is the issue of dietary habits. A high proportion of the patients (81%) said that they started eating healthier foods. Turkish people generally believe that dietary habits are quite relevant with diseases. They tend to believe they can defeat the disease by changing their dietary habits and lifestyle. On the other hand, they commonly believe that dietary modification can even cure cancer. Alternative and herbal Medicine is also much common in Turkey compared to other regions of the world. 64.8% of the participants pointed that they started practising healthy living recommendations such as regular exercise and smoking cessation after the time of diagnosis. These findings are similar with previous reports from other parts of our country [7].

Concerning travelling activities, 48.8% of the patients said that they decreased due to the side effects of treatment. Patients with lower education and elderly had more difficulty as shown in previous reports [8]. Contrary to our expectations, 45% of the females and 54% of the males pointed that the number of their live-in travels and expeditions decreased after diagnosis. This difference between male and female patients was statistically significant. Of the female patients 52.6% and

62% of the male patients had stage 4 or 5 disease which was statistically significant ($p < 0.05$). Therefore, this unexpected result can be explained by male patients' being at advanced stage in a high proportion.

We expected the patients' interests in media (TV, radio and newspapers) would change after the diagnosis of cancer. However, because of the low educational state of the participants, they did not have regular reading habits and this did not change. Also, against our expectations, the type of movies the participants watched did not change.

We observed that more than half of the patients (57.3%) felt optimistic about their diseases in our study. Interestingly, the answers were similar in all age groups (even in the oldest age group). This shows that increased age does not affect the desire to live and optimism. Although cancer is one of the most traumatic events in human life, there is still considerable individual variability in the reactions given to this diagnosis. Despite the general expectations that cancer will evoke unpleasant psychological reactions, major life crisis may also engender positive psychological changes in people's lives [9].

In a study with breast cancer patients, it has been shown that postoperative breast cancer patients who were optimistic were more likely to use problem-focused coping strategies and experienced better emotional outcomes than pessimistic individuals [10].

Being optimistic and considering illness as a challenge increases the likelihood of the mastery of gain. Optimistic individuals with cancer active-

ly take part in setting goals and overcoming the underlying problem, cancer [11].

The present study has considerable importance not only in showing the lifestyle and attitude changes in cancer patients after diagnosis, but also in suggesting coping strategies with the disease. However, it is not without limitations. First, due to its cross-sectional nature, we can not infer a causal relationship. Coping is not a static effort. Therefore, longitudinal studies could provide a more holistic picture of the role of coping in the adjustment of cancer patients. Second, the psychological nature of a cancer patient is labile and therefore periodical interviews are more reliable. Third, family members tend to conceal the stage of the cancer from the patients in order to keep the mood of the patients positive. Information about disease stage may not fully reflect the truth.

Conclusion

Diagnosis of cancer may change the patients' dietary and reading habits, social relationships, activities and more importantly, their point of life view. Patients with cancer think about spending more time with people they love. About half of the patients have negative mood. Thus, psychological and social support for these people is very important.

Conflict of interests

The authors declare no conflict of interests.

References

1. GLOBOCAN-2012: Estimated Cancer Incidence, mortality and prevalence in 2012 http://globocan.iarc.fr/Pages/fact_sheets_population.aspx. Accessed: 15 November 2014.
2. Health Statistics Yearbook, Ministry of Health, 2012, <http://www.sb.gov.tr/TR/dosya/1-87578/h/istat-urk2012> Accessed: 15 November 2014.
3. Tuncer M. An importance of cancer in our country and in the world, disease burden and cancer control politics. In: Cancer Control in Turkey. Koza Press, 2009, Ankara, Turkey.
4. Chlebowski RT, Blackburn GL, Thomson CA et al. Dietary fat reduction and breast cancer outcome: interim efficacy results from the Women's Intervention Nutrition Study. *J Natl Cancer Inst* 2006;98:1767-1776.
5. Boyle T, Fritschi L, Platell C, Heyworth J. Lifestyle factors associated with survival after colorectal cancer diagnosis. *Br J Cancer* 2013;109:814-822.
6. Daher M. Cultural beliefs and values in cancer patients. *Ann Oncol* 2012;23 (Suppl 3):66-69.
7. Yilmaz M, Sanli D, Ucgun M, Kaya NS, Tokem Y. Lifestyle Behaviors and Early Diagnosis Practices of Cancer Patients. *Asian Pac J Cancer Prev* 2013;14:3269-3274.
8. Ristevski E, Regan M, Birks D, Steers N, Byrne A, McGrail MR. Communicating about breast cancer: rural women's experience of interacting with their surgeon. *Aust J Rural Health* 2012;20:22-28.
9. Tedeschi RG, Calhoun LG. Posttraumatic Growth: Conceptual Foundations and Empirical Evidence. *Psychol Inquiry* 2004;15:1-18.
10. Buyukasik-Colak C, Gundogdu-Akturk E, Bozo O. Mediating role of coping in the dispositional optimism-posttraumatic growth relation in breast cancer patients. *J Psychol* 2012;146:471-483.
11. Folkman S, Greer S. Promoting psychological well-being in the face of serious illness: When theory, research and practice inform each other. *Psycho-Oncology* 2000;9:11-19.