Hope and Life Engagement of Cancer Patients at the Advanced Stage

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Abstract

Introduction: Cancer is a clinical tableau in which many complicated physical and psychological problems are encountered and the individual’s defense mechanism against the process is often shaken. With the deterioration of the prognosis and the progression of the disease, individuals whose belief in healing is reduced may lose their life engagement and hope. Objective: The purpose of this cross-sectional and descriptive study is to determine the level of hope and life engagement of individuals with advanced stage cancer. Methods: The study was conducted with 74 advanced cancer patients who were hospitalized in the oncology, palliative care and surgery clinics of the Trabzon Kanuni Training and Research Hospital, fulfilled the research criteria and signed informed consent forms out of their free will. The data were collected using the “Demographic Information Form,” which included subjective questions, the “Integrative Hope Scale” consisting of four subscales, and the “Life Engagement Scale” in which the level of life engagement was detected. The data were analyzed by using the SPSS program and “ANOVA,” “Independent t-test” and “Correlation test” were used to analyze the relationship between the hope and life engagement scores and variables. The value p<.05 was accepted as statistically significant. Results: The common hope level mean of the patients included in the study was 104.5±6.8 and the common life engagement mean was 23.9±4.9. Correlating the significant differences in the subscales of the scale, the variables affecting the level of hope were determined as “living place, fear of death, and despair,” and the variables affecting life engagement were determined as “education status, living place, ruefulness, and needing psychological support.” Conclusions: The psychosocial support and solidarity that the individual receives from other individuals in his environment and health care providers positively affects his self-confidence, hope and life engagement. On the other hand, contrary to the meaning of “I am not afraid of dying,” this statement can be considered an expression of giving up on life. Nurses should focus on the messages underlying what the patients say.

Keywords: Cancer- hope- Life Engagement

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Introduction

Hope is the desire for good things to happen in an individual’s life and is an important defense method in adapting to suffering in life [1]. On the other hand, life engagement involves a process that is directly or indirectly related to the individual’s life goals. Individuals assume a protective role in the face of problems that may arise if their purpose is to give meaning to life [2-3]. When a person is diagnosed with cancer, negative feelings such as fear, anxiety, and despair experienced have an impact on the situational orientation of the patient. Hope is an effective feeling that maintains the individual’s life engagement. By controlling anxiety, it makes the adaptation process easier for patients, allowing them to form a defensive line when they encounter difficulties in the advanced stages of the disease [4]. In terms of these aspects, feelings of hope and life engagement are perhaps most valuable to cancer patients. This was the starting point of this study and our aim was to define the hope and life engagement levels of advanced cancer patients, identify the factors causing a reduction in hope and life engagement, and to contribute to the literature on nursing care by examining what can be done to bring these factors under control.
Materials and Methods

This cross-sectional descriptive study aimed to explore hope and life engagement and the factors that influence hope and life engagement in cancer patients at the advanced stage. A total of 74 cancer patients hospitalized in the palliative, surgery, and oncology clinics between 01 September 2017 and 01 February 2018 in the Trabzon Kanuni Training and Research Hospital were included in the study. The study inclusion criteria were patients who had a cancer diagnosis, were aware of their illness and at stage 3-4 of the disease, were older than 18, literate, and had the mental capacity to understand their situation and problems, were not isolated and could communicate. The researchers informed the patients of the content and aim of the study. A therapeutic approach was used with respect to the condition of the patients and the stage of the disease and an effort was made to maintain a feeling of safety.

Data Collection Tools

A Demographic Information Form, Integrative Hope Scale, and Life Engagement Scale were used in collecting data.

Demographic information form

The researchers prepared the patient questionnaire in line with the related literature [1-4,5]. Data on age, gender, education and other factors were collected along with responses to 10 questions on hope and life engagement. Demographic characteristics of patients; Fifty female, twenty-four male patients participated in this study. Nearly half of the patients were aged 65 and over (48.6%). Of the patients, 27% were literate, 56.8% were primary school and 16.2% were secondary school and university graduates. Fifty two patients were married and 50% of the patients had three children or more. Only four patients were living alone and 43.2% of patients were living in the city.

Integrative Hope Scale

This scale was created by Schrank, Woppmann, Sibitz and Lauber (2011), Sarçam and Akın (2013) studied the Turkish validity and reliability of the scale [5-6]. The scale has 4 subscales and 23 items. The subscales relate to the domains of “trust/faith”, “lack of perspective”, “positive future orientation” and “social relationship / individual value.” All of the questions were scored on a scale of 1, “I strongly disagree” to 6, “I strongly agree.” High scores indicate a higher level of hope, while lower scores in the “lack of perspective” subscales represent higher hope levels. The validity and reliability study determined the Cronbach alpha coefficient to be r= 0.76.

Life Engagement Scale

The Turkish validity and reliability of this scale created by Scheier et al. (2006) were tested by Uğur and Akın (2015). The scale has 6 items and all of the questions were scored on a scale of 1, “I strongly disagree” to 5, “I strongly agree”. Items 1,3,5 are reverse-coded.

Table 1. Means of Life Engagement and Integrative Hope Scales (N=74)

|                      | Min  | Max  | X±SD  |
|----------------------|------|------|-------|
| Life Engagement Scale| 14.00| 30.00| 23.91±4.92 |
| Integrative Hope Scale| 94.00| 129.00| 104.59±6.80 |
| subscales*            |      |      |       |
| trust/faith           | 33.00| 52.00| 42.18±4.12 |
| perspective lack      | 8.00 | 18.00| 14.37±2.75 |
| positive future orientation | 17.00 | 24.00 | 19.37±1.54 |
| social relationship/ individual value | 12.00 | 24.00 | 15.40±2.09 |

*Total scores; Trust/faith 54; perspective lack 36; positive future orientation 24; social relationship/individual value,24

High scores indicate a higher life engagement level. In the validity and reliability study, the Cronbach alpha coefficient is 0.74 for this scale [7-8].

Study permission and ethical approval

International review board approval was received from the Trabzon Kanuni Training and Research Hospital Ethical Committee (Number: 23618724). The patients who agreed to participate (these patients signed a volunteer consent form) were included in the study.

Statistical methods

The Statistical Package for Social Sciences (SPSS) software was used for statistical analyses. For distribution analysis, percentage distributions and averages were used to analyze hope and life engagement scores according to the variables affecting hope and life engagement. The “ANOVA,” “Independent t-test” and “Correlation test” were used to analyze the relationship between the hope and life engagement scores and variables. The value p<.05 was accepted as statistically significant.

Study limitations

That the sampling group consisted of advanced cancer patients and the fact that the study was single-centered are the limitations of the study. The results are specific to the sampling group and cannot be generalized.

Results

Table 1 demonstrates the life engagement and integrative hope scale mean scores of the patients. The results obtained indicate an overall life engagement means of 23.9±4.9 and an overall hope scale mean score of 104.5±6.8. These results show that the patients’ hope levels and life engagement levels were high.

In the examination of the impact of the patients’ sociodemographic characteristics on their levels of hope and life engagement (Table 2), it was observed that patients who had a high school education or higher displayed higher life engagement scores (27.1±2.4) and that the difference in educational level between the groups was statistically significant (p<0.05).

Table 3 shows the environmental factors that could affect the patients’ hope and life engagement and the
Discussion

In this study, which was carried out to determine the hope and life engagement levels of advanced cancer patients, we discuss the findings obtained in the light of the literature. It was discovered that the hope levels among advanced cancer patients are considerably high (104.5±6.8). Other studies of diagnosed cancer cases have also found hope levels to be high [9-10,11]. The reason cancer patients have such high hopes maybe that hope is one of the most important elements of cancer treatment that helps patients to achieve the desired quality of life [12]. Hope is the most basic impetus in the life of a human being. The founder of logotherapy, Viktor Emil Franki, asserts that the most important psychological issue an individual can have is to lack a sense of life’s meaning and to fall into an existentialist void [13]. Hope is the food of the mental core and it should be the most significant part of a nurse’s task to help to maintain that hope under every life circumstance. This is because hope has become recognized as the strongest positive indicator of a cancer patient’s treatment [14].

The location in which the study was carried out was found to be the sociodemographic factor that had an impact
distribution of the mean scores for these factors on the scale. In an examination of the environmental factors that affected the mean scores on the integrative hope scale, it was found that the levels of hope of the patients who had no fear of death (100.8±4.4) and of those who felt hopelessness (102.5±3.2) were lower compared to the other groups and the difference between the groups was significant (p<0.05). It was found that with respect to the environmental factors affecting the life engagement mean scores, patients having regrets about the past (24.9±4.8) and having no need for emotional support (25.3±4.0) had higher levels of life engagement and it was seen that the difference between the groups was statistically significant (p<0.05). The “Positive future orientation” subscale showed that patients feeling rueful about the past were better oriented and the difference between the groups was statistically significant.

As can be seen in Table 5, there is a significant, moderately strong and positive correlation between the integrative hope scale and the life engagement scale (r=0.514, p=0.00).
on the level of hope and life engagement of our patients. The patients living in the district displayed levels of hope and life engagement that were higher than in the other groups. This can be explained by associating this factor with the higher mean scores the patients exhibited in the “trust/faith” subscale of the integrative hope scale. Our outcome indicates that patients who live away from the city in small residential areas feel more secure where they live and as their sense of trust and security rises, it is seen that these individuals become more hopeful. In the small residential areas of the Eastern Black Sea region especially, the family and kinship are still strong threads running through the community and there is a high level of solidarity between friends and relatives in circumstances of birth, death and illness. The “Good relations of the individual with family, neighbors and relatives” may also be one of the reasons people feel more secure in their surroundings.

Our results reveal that patients that have “no fear of death” have lower levels of hope than other groups. Hope is related to health and wellbeing [15]. In this sense, the hopelessness observed in patients who state that they

| Variables                          | "n" (N=74) | "Integrative Hope Scale X ± SD" | P   | "Life Engagement X ± SD" | P   |
|------------------------------------|------------|--------------------------------|-----|--------------------------|-----|
| Diagnosls                          |            |                                |     |                          |     |
| Gis ca                             | 48         | 103.00 ± 4.26                  | 0.302 | 22.87 ± 5.12             | 0.096 |
| Lung ca                            | 16         | 108.00 ± 10.27                 | 0.098 | 25.62 ± 4.37             | 0.096 |
| other**                            | 10         | 106.80 ± 8.03                  | 0.551 | 26.20 ± 3.29             | 0.551 |
| knowledge of disease               |            |                                |     |                          |     |
| Enough                             | 36         | 104.72 ± 5.80                  | 0.098 | 23.94 ± 4.56             | 0.098 |
| partially enough                   | 24         | 102.66 ± 3.87                  | 0.161 | 23.50 ± 4.99             | 0.161 |
| Not enough                         | 14         | 107.57 ± 11.22                 | 0.161 | 24.57 ± 5.91             | 0.161 |
| pain intensity                     |            |                                |     |                          |     |
| Low                                | 20         | 105.50 ± 5.79                  | 0.371 | 24.50 ± 4.28             | 0.371 |
| intensive                          | 10         | 102.60 ± 4.92                  | 0.551 | 25.00 ± 3.77             | 0.551 |
| So intensive                       | 44         | 104.63 ± 7.57                  | 0.551 | 23.40 ± 5.41             | 0.551 |
| Agony                              |            |                                |     |                          |     |
| Yes                                | 34         | 104.52 ± 8.21                  | 0.371 | 23.47 ± 5.63             | 0.371 |
| No                                 | 22         | 106.33 ± 3.49                  | 0.371 | 25.22 ± 4.96             | 0.371 |
| silent*                            | 18         | 103.27 ± 6.35                  | 0.371 | 23.54 ± 3.52             | 0.371 |
| Fear of sleep / darkness           |            |                                |     |                          |     |
| Yes                                | 44         | 104.54 ± 7.36                  | 0.371 | 24.09 ± 5.40             | 0.371 |
| No                                 | 30         | 104.66 ± 5.99                  | 0.371 | 2.66 ± 4.19              | 0.371 |
| Fear of death                      |            |                                |     |                          |     |
| Yes                                | 32         | 104.56 ± 7.20                  | 0.371 | 24.37 ± 4.72             | 0.371 |
| No**                               | 14         | 100.85 ± 4.84                  | 0.371 | 22.28 ± 3.62             | 0.371 |
| silent**                           | 28         | 106.50 ± 6.69                  | 0.371 | 24.21 ± 5.64             | 0.371 |
| Despair                            |            |                                |     |                          |     |
| Yes                                | 48         | 102.50 ± 3.24                  | 0.371 | 23.25 ± 4.45             | 0.371 |
| No*                                | 24         | 105.04 ± 7.44                  | 0.371 | 24.25 ± 5.25             | 0.371 |
| silent***                          | 2          | 119.00 ± 0.00                  | 0.371 | 24.00 ± 0.00             | 0.371 |
| Ruefulness                         |            |                                |     |                          |     |
| Yes                                | 44         | 105.45 ± 7.61                  | 0.371 | 24.90 ± 4.84             | 0.371 |
| No                                 | 30         | 103.33 ± 5.27                  | 0.371 | 22.46 ± 4.96             | 0.371 |
| Longing                            |            |                                |     |                          |     |
| Yes                                | 38         | 104.42 ± 7.98                  | 0.371 | 23.73 ± 5.62             | 0.371 |
| No                                 | 36         | 104.77 ± 5.38                  | 0.371 | 24.11 ± 4.12             | 0.371 |
| Need of psychological support      |            |                                |     |                          |     |
| Yes                                | 46         | 105.43 ± 7.11                  | 0.371 | 21.64 ± 5.49             | 0.371 |
| No                                 | 28         | 103.21 ± 6.13                  | 0.371 | 25.30 ± 4.00             | 0.371 |

* p<0.05 statistical significance group ;**Breast co,Prostate co, Testis co, Soft tissue cancer ;*** n,2 hasn’t been evaluated.
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have no fear of death may be associated with their loss of faith in keeping alive, their belief that they will never again return to their previous state of health, and they are abandoning the battle against death.

We saw in our study that patients who did not feel a sense of hopelessness had a positive orientation concerning the future and their levels of hope were higher. Similar to our findings, Kavradım et al. found that negative feelings about their experiences caused patients to display lower levels of hope and orientation toward the future [1]. The uncertainty surrounding the course of cancer is a factor that increases feelings of hopelessness and anxiety levels. This uncertainty is based on the fear of relapse, loss of control and existential anxiety about life and death [16]. The results of the study revealed an overall mean score on the life engagement scale of 23.9±4.9. A look in the sociodemographic findings related to life engagement indicates that patients with a high school education or higher and patients living in the district displayed higher scores. As the level of an individual’s educational background increases, it is believed that people can feel more determined to reach their goals in life, change their perception of the meaning of life towards a more positive outlook and consequently raise the level of their engagement with life.

Living with regrets about the past was a factor that pointed to a significant outcome as far as life engagement was concerned in our study. Our results suggested that patients with regrets about the past had a higher degree of life engagement. This may be associated with the fact that in their regret over doing or not doing certain things in the past, such patients give life another chance and have no other desire than to make up for the past.

It was found in the study that patients with a need for psychological support had lower levels of life engagement. Patients who have difficulty coping with the psychological stress of the challenging process of the illness consequently grow tired of trying to hold on to life and give up on their will to live. In the process of coping with stress, psychological support is an individual’s best friend on the journey [17-18]. People who do not receive the psychological support they need or somehow

| Variables                      | "trust / faith X± SD" | P    | "Perspective lack X± SD" | P    | "Positive Future Orientation X± SD" | P    | Social relationship / individual value X± SD | P    |
|-------------------------------|-----------------------|------|--------------------------|------|-------------------------------------|------|---------------------------------------------|------|
| Educational status            |                       |      |                          |      |                                     |      |                                            |      |
| No graduation                 | 41,80 ± 5,70          |      | 13,70 ± 2,15             |      | 19,60 ± 2,25                       |      | 16,20 ± 3,27                               |      |
| Primary school*               | 41,95 ± 2,85          | 0.401| 14,95 ± 3,03             | 0.118| 19,19 ± 5,91                       | 0.489| 15,28 ± 1,25                               | 0.701|
| Secondary and higher education| 43,66 ± 4,84          |      | 13,50 ± 2,23             |      | 19,66 ± 1,87                       |      | 14,50 ± 1,67                               |      |
| Living place                  |                       |      |                          |      |                                     |      |                                            |      |
| Village*                      | 39,44 ± 3,46          |      | 14,33 ± 2,56             |      | 19,00 ± 0,97                       |      | 14,66 ± 1,87                               |      |
| Town                          | 43,41 ± 3,52          | 0.03 | 13,83 ± 2,94             | 0.425| 19,41 ± 1,41                       | 0.465| 15,41 ± 1,28                               | 0.161|
| city                          | 42,81 ± 4,28          |      | 14,81 ± 2,71             |      | 19,56 ± 1,86                       |      | 15,81 ± 2,59                               |      |
| Fear of death                 |                       |      |                          |      |                                     |      |                                            |      |
| Yes                           | 42,56 ± 3,38          |      | 15,06 ± 2,88             |      | 19,50 ± 1,606                      |      | 15,56 ± 2,63                               |      |
| No*                           | 39,28 ± 3,45          | 0.01 | 14,71 ± 1,89             | 0.061| 19,28 ± 7,91                       | 0.843| 15,00 ± 1,10                               | 0.709|
| Silent                        | 43,21 ± 4,63          |      | 14,32 ± 2,76             |      | 19,28 ± 1,73                       |      | 15,42 ± 1,79                               |      |
| Despair                       |                       |      |                          |      |                                     |      |                                            |      |
| Yes                           | 42,45 ± 4,17          | 0.154| 14,41 ± 2,87             | 0.902| 19,54 ± 1,51                       | 0.052| 15,45 ± 2,40                               | 0.382|
| No                            | 41,08 ± 3,59          |      | 14,50 ± 2,58             |      | 18,83 ± 1,37                       |      | 15,08 ± 1,21                               |      |
| Ruefulness                    |                       |      |                          |      |                                     |      |                                            |      |
| Yes                           | 42,77 ± 4,22          | 0.136| 14,50 ± 2,93             | 0.638| 19,72 ± 1,40                       | 0.02 | 15,45 ± 2,39                               | 0.795|
| No                            | 41,33 ± 3,88          |      | 14,20 ± 2,49             |      | 18,86 ± 1,61                       |      | 15,3 ± 1,60                                |      |
| "Need of psychological support"|                       |      |                          |      |                                     |      |                                            |      |
| Yes                           | 40,35 ± 4,22          | 0.004| 13,00 ± 2,82             | 0.001| 19,00 ± 1,44                       | 0.094| 15,73 ± 2,27                               | 0.060|
| No                            | 43,30 ± 3,68          |      | 15,21 ± 2,36             |      | 19,60 ± 1,570                      |      | 14,85 ± 1,67                               |      |

*p<0.05 statistical significance group

Table 5. Corelation Between Integrative Hope and Life Engagement Scales

| Integrative Hope Scale | Pearson corelation | P    |
|------------------------|--------------------|------|
| Life Engagement Scale  | 0.514              | 0.000|

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lack this kind of support are more likely to give up on life. Furthermore, previous studies have reported that patients receiving effective psychosocial support exhibit better psychosocial improvement when compared with patients that do not get adequate support. Studies also point out that the patients’ own perceptions of the psychosocial support they receive are even more important [12-19,20]. The positive linear correlation between the hope and life engagement scales makes it clear that for patients with cancer, both emotions feed off of each other. Hope is a valuable emotion that blossoms with the beginning of life, grows with each breath, and encourages the individual to dream, nourishing the need for engaging with life. The challenges an individual faces in life may put a strain on the hope that is a connection to life. Because of this, in trying to touch the psychological inner world of cancer patients, nurses need to focus on revitalizing the patient’s hope and desire for life engagement, on never allowing hope to be abandoned and to ensure that the individual’s holds on tenaciously to life.

In conclusions, It was determined in the study that advanced cancer patients display high levels of hope and life engagement. Furthermore, among the environmental factors that influence levels of hope are the location of residence, fear of death, and feelings of hopelessness and despair and among those that affect life engagement are educational background, the location of residence, ruefulness or regrets about the past and the need for psychological support. It can be said from the study findings that for patients to maintain their existing hope and life engagement, they must rid themselves of their fears, feelings of despair and any other psychological problems they may have. At this point, nursing care can be regarded as the force that can revitalize hope and increase life engagement among cancer patients. This is because the concentrated amount of time nurses spend with their patients, the contact and communication they have with them, and their professional positions as part of the healthcare team provide nurses the important opportunity of adopting a holistic approach to the care of their patients. In this respect, throughout the process of caring for patients with cancer, the nurse needs to focus on facilitating the patient’s acceptance of the treatment, promoting hope and life engagement and working to increase the quality of life. Nurses have a privileged role in talking to patients about their hopes and fears and providing emotional support whenever needed. Nurses should offer their support by making time to talk to their patients, answering questions, acting in a positive and honest manner, providing effective care, and most importantly, being at the patient’s side at any moment of need. It should never be forgotten that the biggest source of support throughout the process is the patient’s family. For this reason, effective communications should be maintained with the patient’s family; the family should be included in the healthcare process and supported from a psychological standpoint. A nurse committed to holistic care should at the same time be sensitive to the patient’s fear of death, feelings of regret and emotions such as hopelessness and provide the care that addresses the patient’s specific needs. Hope is one of the most important emotions of defense needed to hold on to life and holding on to hope is needed to achieve this. Because of this, preventing advanced stage cancer patients from diminished hope and reduced life engagement and making an effort to increase these factors together constitute the best care that can ever be offered. Furthermore, supporting the results of our study with more expanded studies will contribute to increasing the awareness of nurses about this aspect of nursing care. This will help patients with cancer feel a part of a bigger and loving family and ease them along in their struggle.

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Author Contributions

All of the listed authors have seen and approved the final version of the manuscript. All of the authors have met all of the following criteria for authorship, thereby accepting public responsibility for appropriate portions of the content:

1. Substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data
2. Drafting the article or critically revising it for important intellectual content
3. Approval of the version to be published and all subsequent versions

Compliance with ethical standards

The authors declare that they have no conflict of interest.

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