

Original Article

## Investigating the Effect of the Health Status of Patients with Stoma on Illness Perception: Descriptive-Cross Sectional Study

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### Abstract

**Background:** This study was planned to determine the effect of health status of patients with stoma on their illness perceptions.

**Methods:** The study was planned and conducted as descriptive and cross-sectional in order to determine the effect of the health status of the patients with stoma on their illness perception. The population of the study consisted of 100 patients with stoma who met the study criteria. The study data were collected by using “Descriptive Characteristics Information Form” developed in line with the related literature and “Illness Perception Questionnaire” whose Turkish validity and reliability study was conducted by Armay et al. (2007). Ethical and institutional permits were obtained for carrying out the research.

**Results:** It was found that 51% of the participants were female, 47% (n=47) were 61 years old and over, colostomy rate (72%) was higher than ileostomy (28%) rate, patients mostly experienced power loss and fatigue symptoms, mainly stress and anxiety (60%) caused to catch the illness. It was found that 50% of the patients thought that the rest of their life would pass through this disease, and 63% thought it was difficult for their relatives, 70% did not have personal control over the disease ( $p<0.05$ ) and 74% did not understand why.

**Conclusions:** In this study, it can be said that the majority of patients have a positive opinion about the efficacy of the treatment, but they do not understand the disease and this may be related to the psychological effects of the cancer diagnosis as well as the limitations that patients bring to their lives. When the patients’ perceptions on the illness outcomes were evaluated, it was found that the disease was a serious one and created moral and material difficulties on the life.

**Keywords:** Stoma, Health, Cancer, Illness Perception

### Introduction

Emphasizing the importance of social and personal sources as well as physical power, health is the level of meeting the individual’s request and needs, and coping with and changing the environment. Therefore, health is the source of daily life in addition to be the purpose of healthy life. Disease on the other hand including socio-cultural differences represents both objective and subjective mental, physical in individual level and disharmony and imbalance at social level. When the patient feels a difference

or a discomfort in body functions, emotions or physical appearance, such responses vary from individual to individual since the knowledge that the patient has about health and the disease gained by the effect of the culture and beliefs is different (Atesci et.al.2003).

Temporary or permanent colostomy is quite frequently used intervention in surgical practices. Stomas opened due to various reasons affect the quality of life of individuals, limit their daily living activities, reduce the sense of self, and cause the occurrence of the sense of denying in

individuals. It is reported that psychological and physical effects of stoma vary from individual to individual and this difference varies according to the individual's mood, cultural and economic life (Sucu 1998).

In the literature, increase in loneliness, decreased self-confidence, decreased interest in sexuality, suicide attempt, and impaired body image are found in individuals with stomas and they are observed to have both general anxiety disorder and social fear. Stoma can be associated with the reduction in health-related quality of life, increase in social restrictions and deterioration in work and travel activities (Kılıc et.al. 2007).

Illness perception and how the individual perceive the events which have a direct effect on disease process, coping mechanisms and experiences individuals had through the illness period, also have effects not only on psychological, physiological or psychosocial well-being but also on the quality of life and even on the course of the physical disease (Davis et.al. 2011).

According to the studies conducted to determine the correlation between the perception of illness and the disease outcome, the course of disease is emphasized to be better in people who have high internal control perception (Moss-Morris et.al.2002; Ozkan 2007; Knowles et.al.2014).

Based on the view that disease outcomes are not only affected by the disease but also by the individual's illness perception (Knowles et.al.2014), this study was planned to determine the effect of health status of patients with stoma on their illness perceptions.

## Methods

The population of the study consisted of 124 patients with whom stoma was opened between March 2013 and May 2015 in General Surgery Department in a University Hospital. The sample of the study was determined as at least 85 by calculating the number of elements in the population with a known formula. By thinking that there might be a data loss in the study, number of samples was increased approximately 20% and the study was conducted with 100 patients. Data collection form involving two parts which are Descriptive Characteristics Information Form and Illness Perception Questionnaire was filled by the researcher. As the data collection tool in the study, Descriptive

Characteristics Information Form and Illness Perception Questionnaire were used.

Inclusion criteria of the study were determined as;

- Having stoma
- Not having a mental problem
- Being at the level to understand the questions
- Agreeing to participate in the study.

## Data Collection Tools

### *Descriptive Characteristics Information Form*

Within the scope of “Descriptive Characteristics Information Form” developed in accordance with the related literature (Knowles et.al.2014) by the researcher, there are a total of 16 questions that determine the descriptive characteristics (age, gender, marital status, education level, etc.) of the patients with stoma.

### **Illness Perception Questionnaire**

Illness Perception Questionnaire (IPQ) was developed by Weinman (Weinman Petrie and Horne 1996) and reviewed by Moss-Morris et al. in 1996. Turkish validity and reliability study of illness perception questionnaire was also conducted by Armay et al. in 2007. In the study, reviewed form of IPQ was used. The scale consisted of three sections which are symptoms, perception and the causes of the illness.

When Cronbach's alpha internal consistency values of overall scale and its subscales were investigated, Cronbach's Alpha value was determined as 0.627 for overall scale, 0.980 for Duration (Acute/Chronic) subscale; 0.672 for the consequences; 0.907 for Personal Control; 0.825 for Cure Control, 0.900 for Illness Perception; 0.755 for Timeline (Cyclic); 0,913 for Emotional Representations and all subscales were observed to have a good level of reliability (Table 1).

### **Ethical Approach**

To conduct the study, approval from Istanbul University Cerrahpasa Faculty of Medicine Ethics Committee and the permission from I.U. Cerrahpasa Faculty of Medicine, Department of General Surgery were received. Patients who participated in the study were informed about that they are free to participate or not to participate in the study without carrying researcher's responsibilities or any penalty or prejudiced treatment and care risk. Patients'

consents stating that they want to participate in the study were obtained.

### Data Collection

In the study, 100 patients who met the inclusion criteria, came for the control or became in-patient, having stoma opened between 2013 and 2015 in General Surgery Service of a University Hospital were interviewed. Data collection form consisting of two parts, namely, Descriptive Characteristics Information Form and Illness Perception Questionnaire was filled by the researcher and it took 20-30 minutes to collect the data.

### Data Analysis

For the statistical analysis, NCSS (Number Cruncher Statistical System) 2007 (Kaysville, Utah, USA) program was used. When the data of the study were evaluated, Mann Whitney U test was used for two-group comparison of the variables that did not show normal distribution in the quantitative data in addition to descriptive statistical methods (average, standard deviation, median, frequency, rate, minimum, maximum). While Kruskal Wallis test was used in the comparison of three or more groups that did not show normal distribution, Mann Whitney U test was used in the determination of the group that caused differences. Significance was evaluated at  $p < 0.01$  and  $p < 0.05$  levels.

### Results

In this study, 47% of the patients, who participated in the study ( $n=47$ ), were 61 years old and over, 51% ( $n=51$ ) were female, 49% ( $n=49$ ) were male, 66% ( $n=66$ ) were married, 34% ( $n=34$ ) were single, 53% were primary school graduate, 54% had an income lower than the expenses, and 77% had social insurance (Table 2).

When the diagnoses of the patients who participated in the study were examined; while colorectal cancers were observed at the rate of 90% ( $n=90$ ); 10% ( $n=10$ ) were diagnosed to due to the other reasons, 72% ( $n=72$ ) were stoma type colostomy, 28% ( $n=28$ ) were ileostomy, and 48% ( $n=48$ ) had time elapsed after the opening of

stoma was between 0-6 months, 23% ( $n=23$ ) had 6-12 months and 29% ( $n=29$ ) had 12 months and more, and 99% ( $n=99$ ) were determined to be informed about the surgery and its consequences.

A 37% ( $n=37$ ) of the patients stated that they were providing care of the stoma by themselves, 39% ( $n=39$ ) were doing this with the aid of someone and 24% ( $n=24$ ) stated to have the care given by someone else (Table 3).

While "Disease symptoms" under the dimension of the Illness Type of the patients who participated in the study varied between 0 and 10, the mean score was  $6.73 \pm 2.26$  and score median was 7.0 (Table 4).

Duration (Acute/Chronic) score under the dimension of the Patients' Opinions About the Illness varied between 6 and 30, mean score was  $19.51 \pm 10.43$  and score median was 24.0; the Consequences score varied between 6 and 30, mean score was  $22.27 \pm 5.74$  and score median was 24.0;

The personal control scores varied between 6 and 30, mean score was  $23.34 \pm 6.28$  score median was 25.5; the Cure control scores varied between 5 and 25, mean score was  $19.14 \pm 5.67$ , and score median was 21; the score of understanding the illness varied between 5 and 25, mean score was  $15.61 \pm 7.14$ , and median score was 14.5.

The duration (cyclic) scores varied between 4 and 20, mean score was  $14.22 \pm 4.12$ , median score was 13.5; scores of Emotional Representations varied between 6 and 30, mean score was  $20.06 \pm 8.68$ , and median score was 22 (Table 4).

The scores obtained by the patients from Psychological Attributions under Dimension of Illness Causes varied between 6 and 30, mean score was  $19.96 \pm 6.34$ , and median score was 21.

Risk Factor scores varied between 8 and 36, mean score was  $17.71 \pm 5.32$ , and median score was 16; immunization scores varied between 2 and 10, mean score was  $3.91 \pm 1.82$  median score was 4; Accident or Chance scores varied between 2 to 10, mean score was  $4.09 \pm 2.05$ , and median score was 4 (Table 4).

**Table 1. Internal Consistency Values of Illness Perception Questionnaire Subscales  
Reliability Analysis of Illness Perception Questionnaire**

|                                    | <i>Number of questions</i> | <i>Cronbach's Alpha</i> |
|------------------------------------|----------------------------|-------------------------|
| <b>Opinions on Illness</b>         |                            |                         |
| Duration (Acute/Chronic)           | 6                          | 0.980                   |
| Consequences                       | 6                          | 0.672                   |
| Personal Control                   | 6                          | 0.907                   |
| Treatment Control                  | 5                          | 0.825                   |
| Illness Perception                 | 5                          | 0.900                   |
| Duration (Cyclic)                  | 4                          | 0.755                   |
| Emotional Representations          | 6                          | 0.913                   |
| Total                              | 38                         | 0.627                   |
| <b>Dimension of Illness Causes</b> |                            |                         |
| Psychological Attributions         | 6                          | 0.791                   |
| Risk Factors                       | 8                          | 0.506                   |
| Immunization                       | 2                          | 0.272                   |
| Accident or chance                 | 2                          | -0.031                  |
| Total                              | 18                         | 0.513                   |

**Table 2. Distribution of Descriptive Characteristics (N=100)**

|                    |                                    | n  | %    |
|--------------------|------------------------------------|----|------|
| Age                | ≤ 45 Years                         | 17 | 17.0 |
|                    | 46-60 Years                        | 36 | 36.0 |
|                    | ≥ 61 Years                         | 47 | 47.0 |
| Gender             | Female                             | 51 | 51.0 |
|                    | Male                               | 49 | 49.0 |
| Marital Status     | Married                            | 66 | 66.0 |
|                    | Single                             | 34 | 34.0 |
| Lifestyle          | With family                        | 40 | 40.0 |
|                    | Married                            | 50 | 50.0 |
|                    | Alone                              | 10 | 10.0 |
| Residence Place    | Rural                              | 8  | 8.0  |
|                    | Urban                              | 92 | 92.0 |
| Educational status | Literate                           | 17 | 17.0 |
|                    | Primary School                     | 53 | 53.0 |
|                    | High school and higher             | 30 | 30.0 |
| Income Status      | Income is less than Expenses       | 54 | 54.0 |
|                    | Income is equal to Expenses        | 38 | 38.0 |
|                    | Income is more than Expenses       | 8  | 8.0  |
| Cigarette          | Smoker                             | 8  | 8.0  |
|                    | Non-smoker                         | 92 | 92.0 |
| Alcohol            | Using                              | 5  | 5.0  |
|                    | Not using                          | 95 | 95.0 |
| Health Insurance   | SSI                                | 77 | 77.0 |
|                    | Pension fund for the self employed | 9  | 9.0  |
|                    | Retirement fund                    | 13 | 13.0 |
|                    | No Health Insurance                | 1  | 1.0  |

**Table 3. Distribution of variables related to the illness (N=100)**

|                                                     |                              | <b>n</b>  | <b>%</b>    |
|-----------------------------------------------------|------------------------------|-----------|-------------|
| <b>Diagnoses of Disease</b>                         | <b>Colorectal cancer</b>     | <b>90</b> | <b>90.0</b> |
|                                                     | <b>Other reasons</b>         | 10        | 10.0        |
| <b>Stoma Type</b>                                   | <b>Colostomy</b>             | <b>72</b> | <b>72.0</b> |
|                                                     | <b>Ileostomy</b>             | 28        | 28.0        |
| <b>Time Elapsed After Opening the Stoma</b>         | <b>0-6 Months</b>            | 48        | 48.0        |
|                                                     | <b>6-12 Months</b>           | 23        | 23.0        |
|                                                     | <b>≥ 12 Months</b>           | 29        | 29.0        |
| <b>Informing About the Surgery and the Outcomes</b> | <b>Done</b>                  | <b>99</b> | <b>99.0</b> |
|                                                     | <b>Not done</b>              | 1         | 1.0         |
| <b>The Person giving care of Stoma</b>              | <b>Himself/Herself</b>       | 37        | 37.0        |
|                                                     | <b>By the aid of someone</b> | 39        | 39.0        |
|                                                     | <b>By someone else</b>       | 24        | 24.0        |

**Table 4. Distribution of Illness Perception Questionnaire Subscale Scores (N=100)**

|                                                              |                                   | <b>Min-Max (Median)</b> | <b>Mean±SD</b>    |
|--------------------------------------------------------------|-----------------------------------|-------------------------|-------------------|
| <b>Dimension of Illness Type</b>                             | <b>Illness Symptoms</b>           | 0-10 (7.0)              | 6.73±2.26         |
| <b>Opinions about Disease (Illness Perception) Dimension</b> | <b>Duration (Acute/Chronic)</b>   | 6-30 (24.0)             | 19.51±1.043       |
|                                                              | <b>Consequences</b>               | 6-30 (24.0)             | 22.27±5.74        |
|                                                              | <b>Personal Control</b>           | 6-30 (25.5)             | <b>23.34±6.28</b> |
|                                                              | <b>Cure Control</b>               | 5-25 (21.0)             | 19.14±5.67        |
|                                                              | <b>Understanding the Illness</b>  | 5-25 (14.5)             | 15.61±7.14        |
|                                                              | <b>Duration (Cyclic)</b>          | 4-20 (13.5)             | 14.22±4.12        |
|                                                              | <b>Emotional Representations</b>  | 6-30 (22.0)             | <b>20.06±8.68</b> |
| <b>Dimension of the Illness Causes</b>                       | <b>Psychological Attributions</b> | 6-30 (21.0)             | 19.96±6.34        |
|                                                              | <b>Risk Factors</b>               | 8-36 (16.0)             | 17.71±5.32        |
|                                                              | <b>Immunization</b>               | 2-10 (4.0)              | 3.91±1.82         |
|                                                              | <b>Accident or Chance</b>         | 2-10 (4.0)              | 4.09±2.05         |

## Discussion

Illness perception is the cognitive aspects of the illness and patients' beliefs about the illness they have and it is a concept that has a direct effect on experiences the patients live, the illness period and on coping mechanisms (Davis et.al.2011). Patients are reported to try to understand their illness in accordance with their personal experiences, knowledge, values, beliefs, and needs (Weinman, Petrie and Horne 1996). In addition, in the people who had stomas opened due to various reasons, various problems are reported to be experienced by them in terms of physical, psychological, and social view (Taylor et.al.2000; Moss-Morris et.al.2002). It is important to evaluate the illness perception and the patient's psychological response in improving the health conditions and care of the people who underwent stoma surgery.

In the previous studies, the rate of opening stoma was found to be higher for the patients who were male, older than 45 and married (Notter and Chalmers 2012; Repic and Ivanovic 2014; Knowles et.al.2014; Claessens et.al.2015). In this study, most of the patients were found to be female, older than 61, and married (Table 2). Administering the stoma practices in cancer patients usually seen at advanced ages and depending on the structure of Turkish society, a great majority of the patients were married at these ages, which was compatible with the literature (Kılıc et.al.2007; Armay et.al.2007; Lim et.al.2014; Claessens et.al.2015).

In general, stoma is anastomosis of the content of a lumen type organ to the external environment in order to provide a transition different from the normal physiological flow. In surgery, ostomy colostomy and ileostomy are the mostly applied ones according to the frequency order and can be opened as temporary or permanent (Aksoy and Cavdar 2015). Colostomy is anastomosis of the large intestine out of the belly without any sphincter; on the other hand, ileostomy is the anastomosis of the small intestine to the abdominal wall (Kocaman 2007). Temporary stomas are usually opened for a short time period and this time may vary between 3 and 9 months. If anal sphincters are damaged or removed during the surgery, permanent stoma is opened (Burch 2013). In studies, mostly colostomy rate was found to be higher than ileostomy (Carlsson, Berglund and Nordgren 2001; Kılıc et.al.2007). In contract to this result, the number of patients

with colostomy is stated to be lower than the number of patients with ileostomy (Carlsson, Berglund and Nordgren 2001; Moss-Morris et.al.2002; Karabulutlu Yılmaz and Okanlı 2011; Kumcagız and Malazgirt 2000). In this study, colostomy opening ratio in the patients with stoma is found to be higher than ileostomy opening ratio (Table 2).

Colorectal cancers are the most common types of cancers seen after breast in women and prostate cancer in men (Lim et.al.2014). Colorectal cancers whose frequency shows variation depending on the locations are mostly seen in the ascending colon, sigmoid colon and rectum (Akyolcu 2004). In the performed studies, colorectal cancers are the most seen one among the cases requiring stoma opening (Avucan, Imrek and Karaboga 2006; Karabulutlu Yılmaz and Okanlı 2011; Alp 2014). When the reasons why the stoma is opened in the patients participated in this study are examined, the result showing that the majority of them like 90% have the reason of colorectal cancer diagnosis agrees with the results from literature and from the previous study results (Table 3).

Individuals who use their own positive coping mechanisms are known to adjust better to the treatment and the illness. When it is evaluated in this respect, patients with good personal control are determined to cope with the problems effectively (Avucan, Imrek and Karaboga 2006). It is stated in the literature that the thoughts about affecting the patients' health status or controlling them vary (Taylor et.al.2000; Wallston 2004). In this study, majority of the patients are found to have good personal control about the course of the illness (Table 4). When the distribution of subscale total score of the illness perception questionnaire was examined, the personal control mean score was found to be the highest.

In Mols et al.,'s (2014) study, it was determined that the patients think that the illness will continue for a long time and experience serious concerns about their illness and there is deterioration in patients' physical and social roles and their overall health status. In their study, Knowles et al., (2014) reported that health status affected the illness perception significantly. In other studies, deteriorations were also found in the physical, social roles and general health status of patients with stoma (Fucini et.al.2008; Yau et.al. 2009; Hoerske et.al.2010; Bossema et.al.2011). In this study, 50% of the patients

were determined to think that their illness will take long about the course of the illness (Table 4). This result can be interpreted as the fact that stoma care which is not easy and the limitations in the daily living activities are indication of negative effect in patient.

In the studies, patients with high educational level were found to have positive perceptions about the outcomes of the illness (Sucu 1998; Kayıs 2009; Karabulutlu Yılmaz and Okanlı 2011;). In this study, when the patients' perceptions about the results of the illness were evaluated, it is found that the illness was a serious one, created physical and moral difficulties on their life and pushing the caregivers (Table 4). It could be thought that when educational level increased, consciousness level of the patients increased and this had a positive effect on outcomes of the disease.

### Conclusions

Patients were found to experience mostly power loss, fatigue and pain respectively among the illness symptoms, half of the patients thought about the course of their illness that it would take a long time, most of them stated positive opinion about effectiveness of the treatment but they couldn't understand the illness and they were depressed, sad and anxious when they thought about the illness, patients' illness perception increased positively with the increase of the time elapsed after the stoma opening, and young female patients were found to have higher deterioration about the illness perception than the male patients in the duration (cyclic) subscale.

### In accordance with all the results,

It was suggested to plan studies increasing the patients' illness perceptions, informing about what is the disease and what are the symptoms and causes of the illness, providing and maintaining a psychological support after the surgery and discharge starting from the time before the surgery of the patients with stoma and providing and strengthening effective coping with stress for the individuals and their families for the illness itself and the stress resulting from the illness.

### Limitations of the Study

The study was limited with the patients who were willing to participate in the study and had stoma opened between March 2013 and May 2015 in

General Surgery Service of a University Hospital.

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**Place of the study:** Istanbul University-Cerrahpasa Medical Faculty Hospital, Kocamustafapasa Neighborhood, Cerrahpasa Street. No: 53, 34096 Fatih / Istanbul

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