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The Effect of Implementation of Truth-Telling Protocol on Life Expectancy in Patients with Gastrointestinal Cancer

Hassan Abbasi [1], Razieh Froutan [2], Hasan Vosoughinia [3], Kambiz Akhavan Rezayat [4], Azam Rokni [5], Seyed Reza Mazloum [6*]

Abstract

Background: Hope is an important source of human coping when facing problems. Cancer is a common disease which can cause great physical and mental stress for patients, but if the diagnosis is delivered correctly, it can reduce anxiety and confusion for the patient and improve outcomes for both the patient and healthcare staff.

Aim: The present study was performed with aim to determine the impact of implementing a truth-telling protocol on life expectancy of patients with gastrointestinal cancer.

Method: This randomized clinical trial study with a controlled pre-test post-test design was conducted at Mashhad Ghaem Hospital and Pazh Clinic in 2020-2021. Sixty patients with gastrointestinal cancer were divided into two groups: intervention group who received information about their diagnosis using the "truth-telling" protocol, and control group who received standard hospital disclosure of diagnosis. Miller's life expectancy questionnaire was used to collect data before and one month after the intervention.

Results: One month after the intervention, the mean of life expectancy score in the intervention group was 191.56±25.56 and in the control group was 176.93±32.98. The difference between before and after the intervention in the intervention group was -4.41+12.60 and in the control group was -23.02+18.60. There was a significant difference in the mean difference life expectancy score of patients in the control group (p<0.001), but no significant difference was found in intervention group in this regard (p=0.060).

Implications for Practice: The "Truth-Telling" protocol did not lower the life expectancy score in patients with gastrointestinal cancer, so it is recommended to inform the patients about their disease.

Keywords: Cancer, Disclosure of diagnosis, Gastrointestinal cancer, Life expectancy, Truth disclosure, Truth telling

1. Department of Nursing, Bojnurd Faculty of Nursing, North Khorasan University of Medical Sciences, Bojnurd, Iran
2. Associate Professor, Nursing and Midwifery Care Research Center, Mashhad University of Medical Sciences, Mashhad, Iran
3. Associate Professor, Department of Gastroenterology, Faculty of Medicine, Mashhad University of Medical Sciences, Mashhad, Iran
4. Department of Internal Medicine, Imam Reza Hospital, Faculty of Medicine, Mashhad University of Medical Sciences, Mashhad, Iran
5. MSc in Clinical Psychology, School of Humanity Sciences, Azad Islamic University, Shahroud Branch, Shahroud, Iran
6. Department of Medical-Surgical Nursing, School of Nursing and Midwifery, Mashhad University of Medical Sciences, Mashhad, Iran

* Corresponding Author Email: MazlomR@mums.ac.ir

Introduction

Hope is one of the sources of human coping in adapting to problems and even incurable diseases. Also, hope can be described as a healing, multidimensional, dynamic and powerful factor that has an important role in adapting to loss (1). Life expectancy is defined as an inner force which can enrich life beyond pain and suffering. Moreover, lack of hope leads to decreased quality of life and despair. Chronic physical patients, such as those with cancer, realize that hope is an important and unconscious part of their thoughts and feelings. Most research on hope has been conducted in cancer patients because they consider it as a threatening factor following the confirmation of their disease diagnosis (2).

Gastrointestinal cancers are among the most common cancers (3), so that in 2020 in Iran, about 29.4% of new cases of cancer and about 38.7% of cancer deaths were related to digestive cancers (4). Cancer diagnosis is a very unpleasant and unbelievable experience for every person, which causes disruption in job, socio-economic status and family life (5). Cancer patients often have problems in coping with their new situation and may experience serious physical stress and psychological distress (6). After diagnosis of cancer, patients experience severe mental and emotional reactions, so that they feel that they are close to death. Even in cases where there are effective treatments, some patients view a cancer diagnosis as equivalent to death due to mistaken beliefs (5).

One of the most difficult tasks of treatment team is telling bad news to the patient, such as the diagnosis of a life-threatening disease (7). In situations where people's traditional values and habits cause them to react negatively to bad news about a patient's condition, their assessment of the severity of the disease may be unrealistic and inconsistent with medical experts' assessments due to their lack of knowledge (8). In Iranian culture, family support for seriously ill patients play an important role and physicians often share information with the patient's family (9). Therefore, unlike western societies, decisions in eastern societies are mainly family-oriented (10). Also, based on religious beliefs in Islamic countries, it is not acceptable to talk about the time of death (11). Robert Buckman says "If disclosure of bad news is done incorrectly, patients and their families may never forgive us, but if it's well done, they will never forget us" (12). Therefore, despite the difficulty of delivering bad news, a suitable strategy for delivering information to the patients or their family can reduce its difficulty (13).

The truth-telling protocol is a strategy which consists of 6 steps (assessment, planning, preparation, disclosure, support and conclusion) and was designed in 2017 by Ehsani et al. to deliver bad news to patients according to cultural and religious considerations of Iran (11). The evidence shows that disclosure of bad news in a proper way leads to easier acceptance of treatment, greater patient satisfaction and even a decrease in the patient anxiety and increased self-confidence in the medical team, so careful and perspective disclosure of the subject to the patient or family can play a fundamental role in accepting future treatment and care recommendations (14,15). However, studies show that many cancer patients in Iran do not have enough information about their disease (16-18); they ask more information from the treatment team (16-24). Hoseynrezaee et al. stated that most of the cancer patients in their study believed that knowing the truth may make them cooperate more during the treatment period, prevent unnecessary treatments and help them better deal with their disease. They also do not agree with the loss of hope and decrease in quality of life (21). Agha Hosseini et al. (2010) concluded that the awareness of cancer diagnosis did not have a significant negative effect on the level of hope in cancer patients (25). The study by Kao and colleagues in Japan in 2018 also showed that truth telling reduces the patient's confusion and anxiety and does not have a negative effect on the patient's mental health and condition (26).

Life expectancy is one of the factors influencing the treatment process of cancer patients. In Iran, people are often against telling the truth to cancer patients because they believe it may decrease their life expectancy. However, descriptive studies show the opposite results. Therefore, this interventional study was designed and implemented with aim to determine the effect of truth-telling protocols on the life expectancy of gastrointestinal cancer patients.

Methods

This randomized controlled interventional study with a pre-test and post-test design was performed in Mashhad Ghaem Hospital and Pazh gastric disease Clinic in 2020-2021. The sample size was calculated based on the results of a pilot study on 20 people and the mean comparison formula with a

95% confidence factor and a test power of 90%, so that 21 participants were considered in each group (total of 42 subjects). In order to increase the accuracy, 66 eligible patients were selected as the research sample. However, 3 participants in the intervention group due to family non-cooperation and 3 participants in the control group due to the patient's non-cooperation in completing the post-test questionnaire were removed from the study, and finally 60 participants were analyzed (30 in each group) (Figure 1).

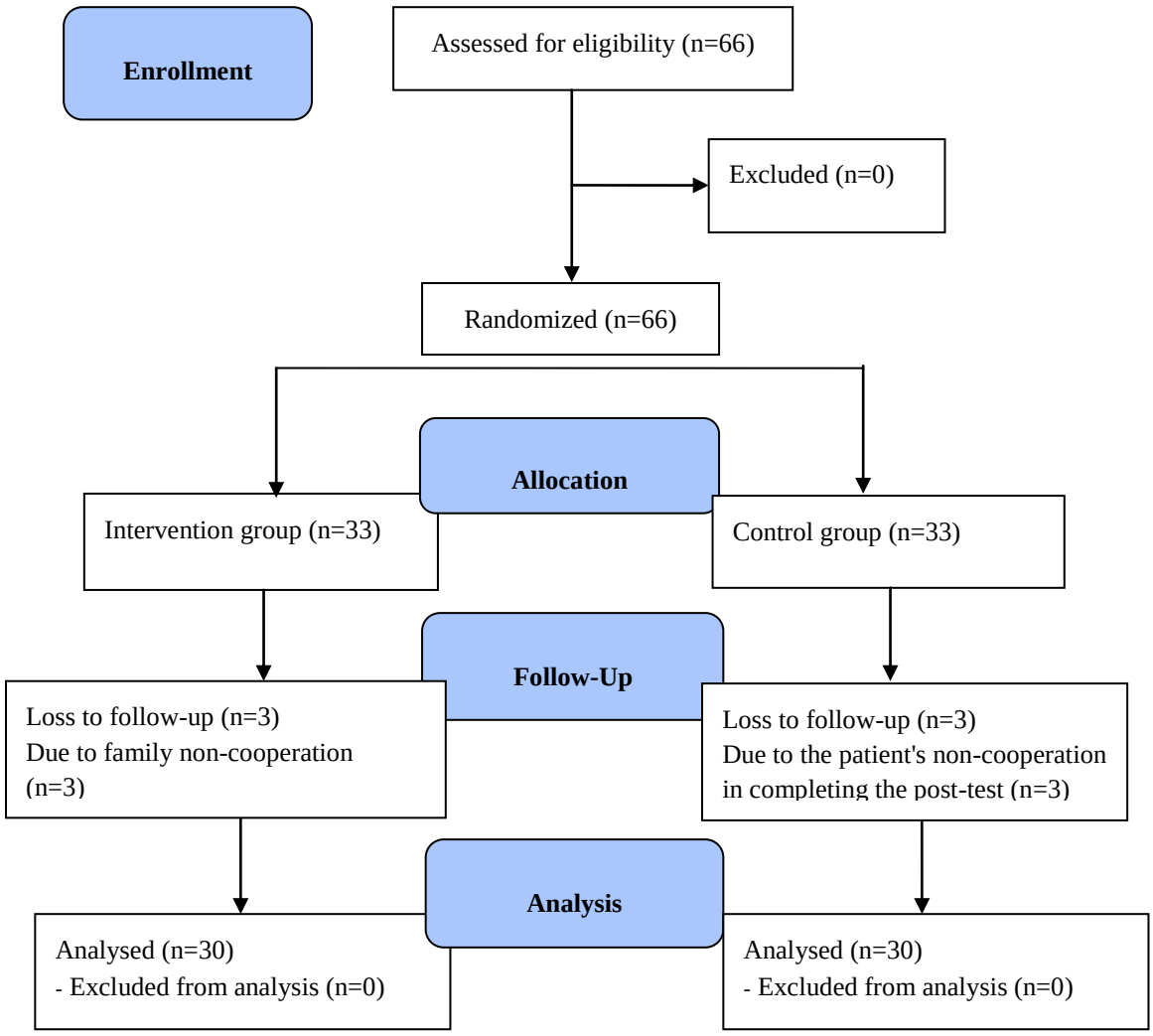

Figure 1. CONSORT flow diagram of the study

Inclusion criteria were: ability to understand and speak Persian, visual and auditory ability and acceptable alertness to answer the questions, suffering from gastrointestinal cancer which was confirmed by a gastroenterologist and biopsy, not previous cancer, no awareness of the cancer diagnosis at the time of admission, age 40 to 70 years, and no significant physical or mental illness (debilitating illness or being under treatment for mental illness). Exclusion criteria were: unwillingness to continue the study and suffering from a significant physical and mental illness during the study. Patients suspected of digestive tract cancer were selected using an available sampling method. They were included in the study if the results of the pathology test confirmed gastrointestinal cancer and they met the inclusion criteria. At first, the demographic information form, Miller's life expectancy questionnaire and the informed consent form were completed by the participants. Then, the patients were divided into two control and intervention groups based on the random sequence created by the randomization site that was created in advance and kept in a closed envelope. The control group received standard hospital disclosure of diagnosis, where physicians do not provide much information unless the patients asked. In the intervention group, at the first suitable time when

all the team members (physician, nurse and psychologist) were present, the patient and family were invited to a special room which was considered for this purpose and had the necessary facilities (chairs, sufficient light, water pitcher and glass, enough space) and disclosure of the cancer diagnosis was done based on the truth-telling protocol (Table 1) (27) by the physician and accompanied by other team members during a 20 to 30-minute face-to-face session . Then, one to three phone calls were made by the researcher to check the patient's condition and answer the possible questions. One month after the final diagnosis, the life expectancy questionnaire was completed by the participants in order to collect information.

Table 1: Steps of the implemented protocol for the intervention group

Steps	Explanation
Assessment	The nurse records patient and family information, pathology in forms and considers patient and family willingness to disclose disease as critical.
Planning	The nurse has to follow a protocol for three possible diagnosis disclosure outcomes. In situation A, both patient and family member agree to be informed. In situation B, patient wants the diagnosis but the family member may not. In situation C, patient prefers their family member to receive the information as they are not yet ready to learn.
Preparation	Preparation involves family, environmental, and patient steps. Family prep in situation B explains importance of diagnosis disclosure. Environmental prep is essential for all situations and involves a private, comfortable room. Patient prep starts during diagnosis disclosure with relevant questions to check understanding.
News disclosure	A truth-telling session should involve a physician, nurse, patient, and family member. Use simple language and disclose information in small increments while checking for understanding. Avoid using the word "cancer" and only give prognosis information when requested and the patient is ready. Instead of giving a specific time frame for death, provide a range based on average life expectancy. Focus on positive aspects over negative.
Support	The physician should give emotional support during truth-telling. The nurse and psychologist may assist in emotional expression and misconception resolution. Additional sessions provide more information and psychological counseling for cancer patients with the presence of team psychologist.
Conclusion	Each team member summarizes important points and answers questions at the end of their respective sessions.

Miller's life expectancy questionnaire has 40 questions which are scored using a grading scale of "strongly disagree, disagree, indifferent, agree and strongly agree". The total score is calculated by adding up the scores (1 to 5) for each statement, with higher scores indicating greater hope. The scoring direction is positive, with a maximum score of 240 indicating maximum hope and a minimum score of 48 indicating minimum hope. The validity of the life expectancy questionnaire in Iran was determined in the study of Abolghasemi, its score was correlated with the score of the anxiety questionnaire (p<0.0001, r=0.79), which indicates that the life expectancy questionnaire has the required validity (28). Also, its validity in the present study was confirmed by seven members of the academic staff using the content validity method. In the Abolghasemi's study, Cronbach's alpha was used to determine the reliability of the life expectancy questionnaire, which was 0.9 (28). This questionnaire was completed two times (at the time of entering the study and one month after the implementation of the intervention or the diagnosis of the disease).

Data were analyzed by SPSS software (version 16). Mann-Whitney and Exact Chi-square tests were used to compare the demographic variables. The Shapiro-Wilk test was also used to assess the normal distribution of Miller's life expectancy mean scores. Since the Miller's life expectancy mean scores show normal distribution, Independent t test was used to determine whether there was a difference between the two groups in the life expectancy mean scores. Also, Wilcoxon and Paired t test were employed to determine the difference in the life expectancy mean scores between before and after the intervention in each group. The results were evaluated at the 95% confidence interval. p<0.05 was considered statistically significant.

Results

The mean age of the patients was 61.58±9.06 years. Most of the patients were female (53.33%), had a sufficient economic status (88.33%), illiterate (30.00%), suffer from colon cancer (28.33%), had no family history of any type of cancer (70.00%), stage II cancer (33.33%), Grade 2 cancer (51.67%) and were undergoing surgical treatment (78.33%). According to the statistical tests, all the above variables were homogeneous in the intervention and control groups (Table 2).

Table 2: Demographic characteristics of gastrointestinal cancer patients in the control and intervention groups

Variable	Frequency (%)		Test Statistic
	Intervention	Control	*P*-value
Age (yrs)[a]	60.27±10.36	62.90±7.50	t= -1.127 P=0.264*
Gender			X^2=1.525 P=0.301**
Male	16 (53.33)	12 (40.00)	
Female	14 (46.67)	18 (60.00)	
Economic status			Z = -0.023 P=0.982***
Lower than enough	1 (3.33)	2 (6.67)	
Enough	26 (86.67)	24 (80.00)	
More than enough	3 (10.00)	4 (13.33)	
Educational level			Z = -1.063 P=0.288***
Illiterate	10 (33.33)	8 (26.67)	
Reading and writing	7 (23.33)	4 (13.33)	
High school	3 (10.00)	4 (13.33)	
Diploma	6 (20.00)	8 (26.67)	
College	4 (13.33)	6 (20.00)	
Digestive system involvement			X^2=8.280 P=0.324**
Esophagus	6 (20.00)	4 (13.33)	
Stomach	7 (23.33)	3 (10.00)	
Vater Ampulla	2 (6.67)	0 (0.00)	
Colon	6 (20.00)	11 (36.67)	
Sigmoid	2 (6.67)	6 (20.00)	
Rectum	4 (13.33)	3 (10.00)	
Liver	1 (3.33)	2 (6.67)	
Pancreas	2 (6.67)	1 (3.33)	
Family history of cancer			X^2=0.317 P=0.573**
Yes	10 (33.33)	8 (26.67)	
No	20 (66.67)	22 (73.33)	
Cancer stage			Z= -1.822 P=0.068***
0	2 (6.67)	3 (10.00)	
I	5 (16.67)	11 (36.67)	
II	11 (36.67)	9 (30.00)	
III	8 (26.67)	5 (16.67)	
IV	4 (13.33)	2 (6.67)	
Cancer Grade			Z=0.556 P=0.578***
1	6 (20.00)	9 (30.00)	
2	17 (56.67)	14 (46.67)	
3	5 (16.67)	5 (16.67)	
4	2 (6.67)	2 (6.67)	
Treatment	7 (23.33)	5 (16.67)	X^2=1.525 P=0.532**
Chemotherapy	1 (3.33)	0 (0.00)	
Radiotherapy	22 (73.33)	25 (83.33)	
Surgery			

[a]Mean±Standard deviation, *Independent t-test, **Exact Chi-square test, ***Mann-Whitney

The comparison of life expectancy score of the patients at the beginning of the study showed that the mean score of life expectancy in the intervention group was 196.03±22.17 and in the control group was 199.90±31.16. Also, one month after implementation of truth telling protocol, the mean score of life expectancy in the intervention group was 191.56±25.56 and in the control group was 176.93±32.98. The difference in life expectancy score after the intervention in the control group was -23.02±18.60 units decrease and in the intervention group -4.41±12.60 units decrease compared to before the intervention. Independent t test showed that the reduction rate of the intervention group was significantly lower than in the control group (p<0.001). Also, Wilcoxon and paired t-test showed that in the control group, the score of life expectancy after the intervention was significantly lower than the pre-test score (p<0.001). But in the intervention group, no significant difference was found between the score of life expectancy after the intervention compared to before the intervention (p=0.063) (Table 3).

Table 3: Mean score of life expectancy in patients with gastrointestinal cancer before and after the intervention in the control and intervention groups

	Mean±SD		t	*P*-value*
	Control	Intervention		
Before intervention	199.90±31.16	196.03±22.17	t=0.562	0.576
After intervention	176.93±32.98	191.56±25.56	t=-1.621	0.060
Difference	-4.41±12.60	-23.02±18.60	t=-4.516	<0.001
	Z=-0.060 P***=0.063	Z=-4.403 P**<0.001		

* Independent t test, **Wilcoxon, ***Paired t test

In the evaluation of the effect of contextual and confounding variables on the score of life expectancy after truth telling in two groups, the results of multivariate tests showed that the independent effect of gender variables (p=0.027) and economic status (p=0.044) and the interaction effect of education level (p=0.012) was significant on life expectancy score after the intervention (Table 4).

Table 4: The result of multivariate tests of the group effect and some demographic and underlying variables on life expectancy

Variable	Total effect	Group effect	Variable effect	Interaction effect
Age*	<0.001	0.244	0.027	0.132
Economic status**	<0.001	0.125	0.044	0.988
Educational level**	<0.001	0.317	0.686	0.012

*ANCOVA test, ** Two-way ANOVA test

Discussion

This study found that using a truth-telling protocol can prevent a decrease in patients' hope, while the control group had a significant decrease in this regard. The results of this study are in line with the studies conducted on the relationship between awareness of cancer diagnosis and the life expectancy of cancer patients in the country and other countries. According to the results of the study by Hoseynrezaee and colleagues (2016), most patients do not agree with hope loss and reduction in quality of life in the case of truth telling (21). Agha hosseini et al. in their study in 2010 investigated the relationship between awareness of cancer diagnosis and hope in cancer patients and concluded that awareness of cancer diagnosis had no significant negative impact on the level of hope in these patients (25). The study conducted in Japan by Kao and colleagues in 2018 also showed that telling the truth reduces the patient's confusion and anxiety and does not have a negative effect on the patient's mental health and condition (26). Also, Mack et al. in 2017 conducted a study on American children with cancer; they concluded that telling the truth about the prognosis by the doctor can increase the patients' hope (29). Hagerty et al. in 2005 conducted a study on 126 American cancer

patients and reported that telling the truth about cancer leads to increased hope in these patients (30). This study contradicts the beliefs of doctors and nurses who oppose telling the truth to cancer patients. It shows that truth-telling and patient awareness does not decrease the life expectancy of cancer patients. However, Almansour and Abdel Razeq (2021) in their research concluded that providing unrealistic hope was viewed as permissible and was preferred over truth telling (31). Such views by the health professionals about false hope are likely to deprive the family members of adequate understanding of the seriousness of the patient's illness. Furthermore, it may deprive the family of the opportunity to be present in the rest of the patient's life and be involved in the decisions of their loved ones. Yerg and Benzin (2015) believed that life expectancy helps patients physiologically and emotionally to endure the crisis of the disease (2). Many families avoid knowing about the disease to prevent and reduce stress in their patients (25), but lying to prevent a decrease in life expectancy can be difficult for doctors and families. In most cases, patients doubt their lies, get upset and look for the truth (32), which itself causes negative effects on the relationship between the doctor and the patient and the dissatisfaction of patient (20).

Feigen et al. (2004) found that many patients (76.9%) informed about their disease during treatment process or due to the side effects of drugs (33). In Iran, Lashkarizadeh et al. reported that informed patients often obtained information indirectly, causing higher levels of psychological distress compared to uninformed patients (16). However, understanding inevitable side effects can limit emotional frustration and increase satisfaction with healthcare services (34). Therefore, educating treatment staff on the benefits of truth-telling can help modify their incorrect beliefs and the benefits of the protocol for both patients and staff members.

The results of the present research showed that the level of life expectancy is related to the age of the patients. Other studies also mentioned the relationship between the age of patients and their level of hope (35-37). However, Pourghazneyn et al. (2003) in their study reported that the level of hope is not related to the patients' age (38). The reason for this discrepancy could be due to the difference between the mean age of the studied subjects. Also, the results of the present study showed that the level of life expectancy is related to the economic status of the patients, which is in line with the results of the study by Pourghazneyn et al. (2001) (39). This relationship is probably due to easier purchasing and better access to medical services by those with higher economic status. Moreover, the results of the present study showed that the level of life expectancy is related to the level of education of the patients. Other researchers also reported the similar results (36,37). The reason for this relationship is probably related to the level of information and awareness of people. However, Porghazneyn et al. (2003) reported that the level of hope is not related to the level of education (38). Teaching the truth about cancer to treatment staff and students can benefit patients by increasing their life expectancy.

This research had some limitations, including uncontrollable factors such as personality, psychological, cultural, and religious characteristics that affect people's reactions to cancer diagnosis. However, a control group and random allocation helped mitigate these effects. In addition, some families didn’t cooperate due to cultural taboos surrounding cancer in Iran, resulting in more cases of non-cooperation in the intervention group than the control group. Future research can investigate the protocol's effect on informing other types of cancer or diseases like AIDS.

Implications for practice

In many Eastern and Middle Eastern countries, including Iran, families fear negative effects, low morale, and loss of hope after disclosing a cancer diagnosis. This belief can prevent patients from making informed decisions and cause side effects and problems for the treatment staff and society. However, delivering bad news in a principled way and respecting cultural and religious principles lead to patients better accept their condition and improve long-term benefits such as cooperation and life expectancy.

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Conflicts of interest

The authors declared no conflict of interest.

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