



Assessment of the Quality of Life Among Patients under Palliative Care

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Abstract

Background: Palliative care is a form of medical care that focuses on providing comfort and pain relief to patients with severe, incurable diseases. The World Health Organization defines quality of life as “an individual’s perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”. Quality of life and palliative medicine represent two aspects that should be inseparable in the comprehensive care and treatment of a patient at the end of life.

Objectives: The aim of this study was to assess quality of life among patients under palliative care using the WHOQOL-BREF and EQ-5D questionnaire.

Material and methods: The study included 100 consecutive patients admitted to palliative care between September 2018 and January 2019 being treated in a hospice and at home. A three-part survey process was used to collect data, including the following: Demographic Data Form; WHOQOL-BREF questionnaire; EQ-5D questionnaire.

Results: The WHOQOL-BREF questionnaire was analyzed for 4 domains. The study obtained the following results: Domain 1=40.2; Domain 2=39.94; Domain 3=36.1; Domain 4=37.7. According to the guidelines of the EQ-5D questionnaire, it was shown that 43% of patients are unable to walk or have serious problems with walking, 59% of patients are unable or have serious problems with self-care, 61% of patients are unable or have serious problems with ordinary activities, 52% of patients have severe or extreme pain/discomfort, 65% of patients are very anxious or depressed.

Conclusions:

1. The study showed that patients covered by palliative care present low indicators of quality of life.
2. According to the data obtained, palliative care programs should pay special attention to the improvement of quality of life by taking an interdisciplinary approach to its resources.

Background

Palliative care is a form of medical care that focuses on providing comfort and pain relief to patients with severe, incurable diseases. It involves a comprehensive approach to patients and their needs, including care of disease symptoms and of the patient's emotions and spirituality. Palliative care can be provided by palliative medicine specialists, palliative nurses, social workers, psychologists, chaplains and volunteers, in addition to psychologists and physiotherapists. The goal of palliative care is to improve the quality of life of the patient and their family by providing physical, mental and spiritual support [1, 2, 3].

Quality of life includes the ability to function mentally, physically and socially in the face of limitations caused by the disease. The World Health Organization (WHO) defines quality of life as "an individuals' perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [2, 4, 5, 6].

The diagnosis of malignant disease results in major changes in the lifestyle. These changes involve the emotional and physical spheres. They are caused by discomfort, pain, disfigurement, dependence and loss of self-esteem. Malignant disease carries with it a stigma and a state of finitude considered by many as incurable. It has been shown that more than 50% of cancer patients have five common symptoms that can disrupt perceptions of quality of life: pain, weakness, fatigue, weight loss, lack of energy [7, 8].

Data from a systematic review showed that personal autonomy, physical fitness, social, emotional, cognitive and spiritual status, as well as health care and preparation for death, are important aspects of quality of life for people with incurable diseases [9].

Over the years, different approaches aimed at improving quality of life at its end have been taken. At first, assumptions similar to the medical one – return to the pre-disease state – were used. However, they were difficult to implement in the group of palliative patients. The focus was then on the psychological area of neutralizing symptoms such as anxiety, depression, irritability, and some cognitive dysfunction. This was possible, thanks to

psychopharmacological treatment modalities or forms of psychological assistance directed at the same goal [10].

Available research shows that the use of self-help programs improves quality of life in the realm of stress relief, increases feelings of independence, reduces the intensity of physical complaints and improves mood [10, 11].

Palliative medicine refocuses the importance of medical procedures from curing the disease to alleviating its symptoms. One of the most important activities is the reduction of somatic complaints. In this regard, the priority of palliative care is to take care of a better quality of life for patients [3].

Quality of life and palliative medicine represent two aspects that should be inseparable in the comprehensive care and treatment of a patient at the end of life. Therefore, the aim of this study was to assess quality of life among patients under palliative care [12, 13].

Material and methods

The study included 100 patients admitted consecutively to palliative care between September 2018 and January 2019 being treated in a hospice and at home. The main pathologies of the study group were lung (20%; n=20), breast (20%; n=20) and gastric cancers (12%; n=12). All were in a state of progressive disease. The study was part of normal routine treatment and did not require medication. All procedures conducted during the study respected the standards of institutional and/or national ethics committees, as well as the Helsinki Declaration (1964) and its subsequent amendments. All participants were thoroughly informed about the study. The inclusion criterion was a Karnofsky score above 20%, obtained at the time of visit. Subjects in the terminal stage of disease were excluded. Participation in the study was voluntary and anonymous.

A three-part survey process was used to collect data, including:

- A demographic Data Form containing socio-demographic characteristics of patients (i.e., age, gender, BMI, education level, marital status, household income),
- A World Health Organization Questionnaire (WHOQoL-BREF),
- An EQ-5D Questionnaire.

Patients answered all three questionnaires in a single session. Socio-demographic characteristics were developed first, followed by the WHO-QoL-BREF, and finally the EQ-5D. When asked for assistance, the researcher was limited to slowly rereading the items. When the patient was not sure which answer to choose, they declared the first one that came to mind. The research tools used are described in detail below:

Demographic data form

This is a form that includes the socio-demographic characteristics of patients with a focus on:

- age,
- gender,
- BMI,
- education level,
- marital status,
- household income.

WHOQOL-BREF form

The WHOQOL-BREF was developed by the World Health Organization (WHO) and is considered a universal tool given the fact that it can be used in all countries and cultures. It can be used by physicians, researchers and health care decision-makers to measure the impact of disease, therapy and environment on patients' quality of life. The WHOQOL-BREF is a shorter version of the extensive WHOQOL-100 and is recommended in situations where it is important to reduce respondent burden. It consists of 26 questions, including 2 general questions on quality of life and health, and 24 questions on the four domains of quality of life: physical; psychological, social, environmental.

The questions identified situations in the past 4 weeks [3, 14, 15].

EQ-5D Questionnaire

The EQ-5D is a standardized instrument for measuring health-related quality of life. It is a widely used tool in health economics, clinical research and population health studies. The EQ-5D consists of a descriptive system and a visual analog scale.

The descriptive system includes five dimensions of health: mobility; self-care; usual activities; pain/discomfort; anxiety/depression. Each dimension has five levels: no problems; minor problems; moderate problems; major problems; inability/severe problems. Respondents are asked to indicate their level of health in each dimension. In addition, the questionnaire includes a visual analog scale that measures the person's overall health. It takes values from 0 (the worst health condition imaginable) to 100 (the best health condition imaginable). The parameters refer to the patient's condition "as of today". The EQ-5D has been translated into many languages and has been used in various settings. The EQ-5D is widely used in health economics and health outcomes research to assess the impact of health interventions and compare the effectiveness of different treatments [16, 17].

The results were collected and analyzed using Microsoft Excel spreadsheet and Statistics 17.0 oraz Statistica 10. The following were used for statistical analysis: Pearson correlation; Student's t test and post hoc analyses (NIR – Nearest Significant Differences).

Results

The study included 70% (n=70) women and 30% (n=30) men. The average age of the study group was 55.81. The vast majority 55% (n=55) of the study group had a high education level. The average net income per household member was 1828.40 (SD=310.69). The analysis of morphotic parameters and main patient pathologies among the studied group of patients is presented below.

Table 1. Analysis of morphotic parameters among the studied group of patients

Variable	M	Minimum	Maximum	SD
AGE	55,81	45	71	8,58
BMI	21,5	15,9	34,1	4,9

Table 2. Main patient pathologies

Men			Woman		
Pathology	N	%	Pathology	N	%
Malignant cancer of bronchi and lung	7	7%	Breast cancer	20	20%
Prostate cancer	5	5%	Malignant cancer of bronchi and lung	13	13%
Colon cancer	4	4%	Stomach cancer	8	8%
Stomach cancer	4	4%	Colon cancer	7	7%

The marital status of respondents was analyzed next. A chart is shown below

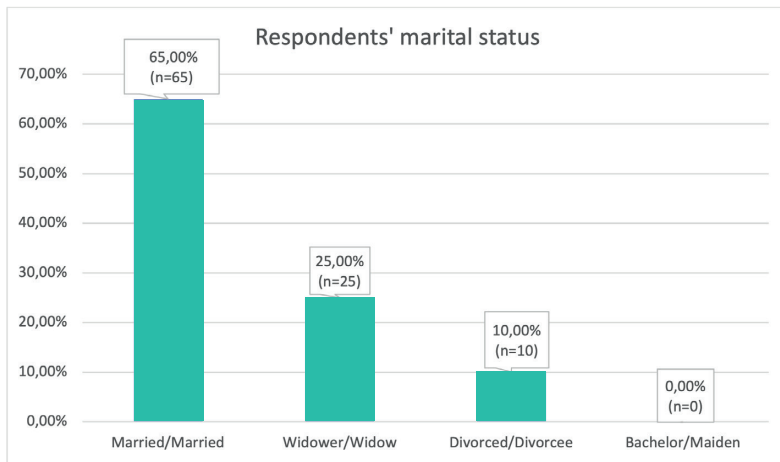


Figure 1. Marital status of respondents

Subsequently, the first research tool was analyzed

Table 3. Descriptive analysis of the WHOQOL-BREF form

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	39% (n=39)	32% (n=32)	18% (n=18)	11% (n=11)	0% (n=0)
		Very dissatisfied	Fairly dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	41% (n=41)	41% (n=41)	14% (n=14)	3% (n=3)	1% (n=1)
		Not at all	A small amount	A moderate amount	A great deal	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	0% (n=0)	18% (n=18)	16% (n=16)	38% (n=38)	28% (n=28)
4.	How much do you need any medical treatment to function in your daily life?	4% (n=4)	8% (n=8)	26% (n=26)	36% (n=36)	26% (n=26)
5.	How much do you enjoy life?	39% (n=39)	24% (n=24)	14% (n=14)	15% (n=15)	8% (n=8)
6.	To what extent do you feel your life to be meaningful?	26% (n=26)	46% (n=46)	13% (n=13)	15% (n=15)	0% (n=0)
		Not at all	Slightly	Moderately	Very	Extremely
7.	How well are you able to concentrate?	25% (n=25)	20% (n=20)	22% (n=22)	31% (n=31)	2% (n=2)
8.	How safe do you feel in your daily life?	28% (n=28)	33% (n=33)	19% (n=19)	15% (n=15)	5% (n=5)
9.	To what extent is your environment conducive to health?	22% (n=22)	33% (n=33)	25% (n=25)	12% (n=12)	8% (n=8)

		Not at all	Slightly	Somewhat	To a great extent	Completely
10.	Do you have enough energy for everyday life?	19% (n=19)	58% (n=58)	15% (n=15)	6% (n=6)	2% (n=2)
11.	Are you able to accept your bodily appearance?	39% (n=39)	22% (n=22)	20% (n=20)	16% (n=16)	3% (n=3)
12.	Have you enough money to meet your needs?	28% (n=28)	35% (n=35)	35% (n=35)	1% (n=1)	1% (n=1)
13.	How available to you is the information you need in your daily life?	32% (n=32)	29% (n=29)	26% (n=26)	11% (n=11)	2% (n=2)
14.	To what extent do you have the opportunity to pursue your interests?	18% (n=18)	41% (n=41)	26% (n=26)	9% (n=9)	6% (n=6)
		Not at all	Slightly	Moderately	Very	Extremely
15.	How do you find yourself in this situation?	35% (n=35)	27% (n=27)	29% (n=29)	9% (n=9)	0% (n=0)
		Very dissatisfied	Fairly dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	34% (n=34)	26% (n=26)	25% (n=25)	13% (n=13)	2% (n=2)
17.	To what extent are you satisfied with your performance in daily life?	33% (n=33)	43% (n=43)	17% (n=17)	5% (n=5)	2% (n=2)
18.	How satisfied are you with your capacity for work?	33% (n=33)	34% (n=34)	22% (n=22)	11% (n=11)	0% (n=0)
19.	How satisfied are you with yourself?	27% (n=27)	31% (n=31)	27% (n=27)	13% (n=13)	2% (n=2)

		Very dissatisfied	Fairly dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
20.	How satisfied are you with your personal relationships?	30% (n=30)	27% (n=27)	23% (n=23)	14% (n=14)	6% (n=6)
21.	How satisfied are you with your sex life?	34% (n=34)	31% (n=31)	21% (n=21)	13% (n=13)	1% (n=1)
22.	How satisfied are you with the support you get from your friends?	14% (n=14)	36% (n=36)	21% (n=21)	20% (n=20)	9% (n=9)
23.	How satisfied are you with the conditions of your home?	18% (n=18)	32% (n=32)	16% (n=16)	19% (n=19)	15% (n=15)
24.	How satisfied are you with your access to health services?	14% (n=14)	29% (n=29)	45% (n=45)	11% (n=11)	1% (n=1)
25.	How satisfied are you with your transport?	15% (n=15)	46% (n=46)	16% (n=16)	15% (n=15)	8% (n=8)
		Never	Infrequently	Sometimes	Frequently	Always
26.	How often do you have negative feelings such as sadness, despair, anxiety, or depression?	1% (n=1)	11% (n=11)	22% (n=22)	40% (n=40)	26% (n=26)

Table 4. Domain analysis of the WHOQOL-BREF form

		Raw score	Transformed scores*			
			4-20		0-100	
27.	Domain 1 Somatic	a. = 18,08 / SD=2,84	b: 10,47 / SD=1,55	Me=11	c: 40,2 / SD=10,53	Me=41
28.	Domain 2 Psychological	a. =15,44 / SD=4,61	b: 10,46 / SD=3,12	Me=10	c: 39,94 / SD=19,16	Me=38
29.	Domain 3 Social	a. = 7,29 / SD=3,05	b: 9,85 / SD=4,08	Me=8	c: 36,1 / SD=25,75	Me=25
30.	Domain 4 Environmental	a. = 19,57 / SD=6,21	b: 10,05 / SD=3,06	Me=9	c: 37,7 / SD=19,13	Me=31

The second survey tool was then analyzed

Table 5. Descriptive analysis of the EQ-5D-5L questionnaire

	Mobility	Self-care	Usual activities	Pain / Discomfort	Anxiety / Depression
Level 1 (No problems)	1% (n=1)	1% (n=1)	2% (n=2)	0% (n=0)	1% (n=1)
Level 2 (Slight problems)	13% (n=13)	9% (n=9)	5% (n=5)	18% (n=18)	11% (n=11)
Level 3 (Moderate problems)	43% (n=43)	31% (n=31)	32% (n=32)	30% (n=30)	23% (n=23)
Level 4 (Severe problems)	41% (n=41)	45% (n=45)	43% (n=43)	35% (n=35)	53% (n=53)
Level 5 (Extreme problems/ unable to function)	2% (n=2)	14% (n=14)	18% (n=18)	17% (n=17)	12% (n=12)
Total	100% (n=100)	100% (n=100)	100% (n=100)	100% (n=100)	100% (n=100)

The health of respondents was declared at an average level of 45.07% (Min=20, Max=80, SD=11.84). Below is the result grouped based on 5 percentage dimensions:

Table 6. Descriptive analysis of the EQ-5D-5L health aspect questionnaire

	0–20 %	21–40 %	41–60 %	61–80 %	81–100 %
Health	1% (n=1)	53% (n=53)	42% (n=42)	4% (n=4)	0% (n=0)

Statistical analysis

Results of the variables studied for two research tools were analyzed. For this purpose, a Pearson correlation coefficient was used. All studied domains of the WHOQoL-BREF questionnaire (somatic, psychological, social, environmental) correlate significantly with all studied aspects of the EQ-5D questionnaire (mobility, self-care, usual activities, pain/discomfort, anxiety/depression). The somatic and psychological domains correlate most strongly with "usual activities", the correlations are high at: $r=0.754$ and $r=0.797$, respectively. The social domain has the highest correlation with "self-care" $r=0.751$ and "usual activities" $r=0.735$. The environmental domain has the highest correlation with "usual activities" $r=0.752$.

Next, the correlation of age in relation to the individual results of research tools was analyzed. Pearson correlations were used for this purpose.

WHOQoL-BREF Questionnaire

Age correlates significantly negatively with each of the domains: somatic ($r=-0.277$), psychological ($r=-0.439$), social ($r=-0.413$), and environmental ($r=-0.516$). Thus, the values in each domain decrease significantly with age. Comparing the correlation coefficients, in this case, age has the greatest relationship with the environmental domain, and the least with the somatic domain.

EQ-5D Questionnaire

Age is also significantly related to mobility ($r=-0.518$), self-care ($r=-0.264$), usual activities ($r=-0.364$), pain/discomfort ($r=-0.163$), anxiety/depression ($r=-0.290$). In each of these aspects, there is a significant correlation with a negative direction. Thus, evaluations of the above-mentioned spheres deteriorate with age in the respondents' opinion. Comparing the correlation coefficients, the strongest relationship is observed with mobility, and the weakest with pain.

Next, the results of research tools were compared according to the subjects' gender. For this purpose, the Student's T-test was carried out. Only the environmental domain and the pain/discomfort scale showed significant gender differences. In the other subscales, the intergender differences are not statistically significant. Women have a significantly higher score on the

environmental scale ($M=20.47$) than men ($M=17.47$) $p=0.026$, and a higher level on the pain scale ($M=2.67$) than men ($M=2.07$) $p=0.004$.

The relationship between BMI and the different domains of the WHO-QoL-BREF questionnaire was also analyzed. Pearson correlations were used for this purpose. BMI correlates significantly negatively with the somatic domain ($r=-0.217$). There is a negative relation, i.e., the higher the subjects' BMI the worse they rate their quality of life in the somatic domain.

The relationship between BMI and the results of the EQ-5D-5L questionnaire was also analyzed using Pearson correlation. BMI correlates significantly positively with mobility ($r=0.257$), pain/discomfort ($r=0.263$), anxiety/depression ($r=0.298$) and health evaluation values ($r=0.206$). This means that the higher the BMI, the better patients rated their ability to move, the less pain/discomfort they experienced, the less anxiety/depression they had, and the better their assessment of their health was.

The relationship between marital status and the results of WHOQoL-BREF and EQ-5D questionnaire was also analyzed. Post-hoc analysis (NIR – Nearest Significant Differences) was used. The following significant relationships were obtained ($p<0.05$):

- Married people have a significantly higher score in the somatic domain than widowers and divorced people,
- Married people have a significantly higher score in the psychological domain than widowers,
- Married people have a significantly higher score in the social domain than widowers,
- Widows and widowers have a significantly lower score in the mobility domain than married and divorced people,
- Married people rate their abilities in usual activities significantly better than widowers,
- Divorced people rate their pain levels significantly worse than widowers,
- Divorced people have significantly lower levels of anxiety than widowers,

- Widows and widowers rate their health significantly lower than married and divorced people.

Discussion

The study presented here was designed to analyze the quality of life of a population of patients under palliative care during a crisis period in their lives. Incurable cancer, with no prospect of recovery, poses a huge challenge in terms of good mental health closely correlated with good quality of life. In the initial phase, cases of deteriorating moods are already observed practically on a daily basis by medical staff providing palliative support.

The WHOQOL-BREF questionnaire is one of the most popular quality-of-life assessment tools recommended by the WHO. Therefore, it was decided to use this questionnaire to assess quality of life [4].

In our own research, the vast majority of respondents (71%) identified their quality of life as bad or very bad (Q1 of the WHOQOL-BREF questionnaire). This is a result that undoubtedly proves the validity of conducting a study to accurately assess quality of life, and consequently to apply adequate measures to improve it. The thesis presented here is related to the general principles of palliative medicine, i.e., the provision of comprehensive medical, psychological, spiritual and social care for the patient and his family at the end of the patient's life.

The WHOQOL-BREF questionnaire, according to the instructions for using the research tool, was analyzed in terms of 4 domains (somatic, psychological, social and environmental). The following results were obtained in the study after the data were converted to a 0–100 scale (SD values are given in parentheses): Domain 1=40.2 (10.53); Domain 2=39.94 (19.16); Domain 3=36.1 (25.75); Domain 4=37.7 (19.13). Similar research results were obtained by Komal Kashyap and co-authors studying a group of patients under palliative care in India. The researchers used the same survey instrument. The authors obtained the following results: Domain 1=34,107 (8,784); Domain 2=39,791 (10,838); Domain 3=50,833 (11,448); Domain 4=44,921 (8,028). A significant difference can be noted by comparing domain 3 (social). It was presented at a lower level in the Polish population [18].

Quite similar results were shown by Bui Thanh Huyen and co-authors studying Vietnamese patients with advanced cancer. The researchers showed median somatic, psychological, social and environmental domains, respectively: 12; 12.67; 13.07 and 12.73, while our own study showed it at: 11; 10; 8; 9. Both groups of results were shown after converting the results to a range of 4–20. Adopting 12 as the midpoint between very bad and very good conditions, the participants of the Polish studies declared slightly lower ratings for each domain of the quality of life [19].

Another research tool shown in the study was an analysis of the quality of life of palliative care patients using the EQ-5D-5L questionnaire. The results were analyzed according to the guidelines for using the research tool [17]. In a meta-analysis by Ida Røed Flyum and co-authors compiling 710 studies, it was shown to be one of the most popular research methods for assessing health-related quality of life [20]. Similar recommendations are made by Lepert W. and co-authors [21].

In 2014, Golicki D. and Niewada M. presented the Polish standards of the EQ-5D-5L questionnaire recommended by the authors of research tool. The estimated data was presented based on 3963 questionnaires. No problems among the parameters of the survey tool were reported: Mobility – 74.2%; Self-care – 90.9%; Usual activities – 82.6%; Pain/discomfort – 47.8%; Anxiety/depression – 58.5%. For health, the accepted Polish norms are estimated at 88%. In our own study, no problems in the individual parameters of the survey tool were reported: Mobility – 1%; Self-care – 1%; Usual activities – 2%; Pain/discomfort – 0%; Anxiety/depression – 1%. Respondents in palliative care declared the level of health at 45.07% on 100% scale [22].

The presented comparison shows the large differences between the studied group of patients under palliative care and the accepted norms for Polish citizens. The above comparison illustrates how low values of the quality-of-life parameters are presented by the studied group of patients.

The present study showed that 43% of patients are unable to walk or have severe problems with their gait, 59% of patients are unable or have severe problems with self-care, 61% of patients are unable or have severe problems with usual activities, 52% of patients experience severe or extreme

pain/discomfort, 65% of patients are very anxious or depressed. Similar results were shown by Ciećko W. and his co-authors studying a group of Polish patients under palliative care. The authors showed the above aspects at levels of respectively: 70,9%; 60,5%; 51.9%; 43,2%; 32,1%. Differences in the described set can be noted in the aspects of gait and anxiety/depression [23]. Comparison of results on "How is your health today?" respondents declared results of 45.07% in the health scale. Ciećko W. and his co-authors showed this aspect at 51.4%. The authors of the study showed in their conclusions that patients receiving palliative care have a significant reduction in quality of life [23].

Terminal cancer, with its severe physical symptoms and psychosocial burdens, represent an existential threat and a major stressor for patients and their caregivers [24, 25]. The factors described undoubtedly reduce quality of life among palliative patients. The results of our own studies as well as those of other authors show this evident problem. Our own studies have shown that quality of life is reduced in every aspect. One of the factors observed is the acceptance of disease, coming to terms with the end of life, as well as the progressive lack of independence. One of the sensors to prevent a drastic decline in quality of life should be the implementation of interdisciplinary palliative care aimed at addressing the real needs of these patients [26]. Accordingly, quality of life, in addition to its mere investigation, should be constantly improved using the resources of an interdisciplinary medical team. Therapy carried out in this way can significantly increase patients' level of independence, and thus increase their quality of life, as shown in our own and other authors' studies.

Conclusions

1. The study showed that patients covered by palliative care present low indicators of quality of life.
2. In a comparison of WHOQOL-BREF questionnaire results, the lowest rates were recorded in the social domain.

3. Respondents reported a problem in each sphere of the EQ-5D-5L questionnaire, with the highest percentage describing them as severe and moderate problems.
4. According to the data obtained, palliative care programs should pay special attention to the improvement of quality of life by taking an interdisciplinary approach to their resources.

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