



# Normalization of the AIS (Acceptance of Illness Scale) questionnaire and the possibility of its use among cancer patients

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## Abstract

**Introduction and Objective.** Cancer triggers many negative emotions in patients which affect the quality of life and low acceptance of the illness. The level of acceptance of illness is related to the level of pain and the degree of compliance with medical recommendations. The aim of the study is evaluation of the use of the Acceptance of Illness Scale (AIS) among people with cancer.

**Materials and Method.** The study involved 1,187 patients (666 women aged 21–96 (M=58.17; SD=12.88) and 521 men aged 22–96 (M=67.12; SD=13.75) diagnosed with malignant cancer under outpatient care of the Maria Skłodowska-Curie Institute – Oncology Center in Warsaw. An acceptance of illness questionnaire developed by B. J. Felton, T. A. Revensson and G. A. Hinrichsen was used.

**Results.** Socio-economic (education, place of residence, income, professional status) and medical (occurrence of metastases, type of treatment used) factors affect the level of acceptance of illness by patients. Stent standards were developed to determine the level of acceptance of illness in the low-average-high categories.

**Conclusions.** The Acceptance of Illness Scale (AIS) should be used in the case of cancer patients. Assessment of the patient's acceptance of illness, as well as the factors affecting acceptance, will allow for the planning of appropriate treatment and psychotherapeutic support for specific patients, whose level of acceptance of illness is the lowest.

## Key words:

cancer, normalization, AIS

## INTRODUCTION

Quality of life is one of the factors affecting not only life satisfaction, but also to a large extent determines feelings related to the disease; it also affects the patients' life expectancy. Factors affecting the level of quality of life include pain and acceptance of illness. Pain is one of the main symptoms reported by patients with cancer [1, 2, 3, 4] and acceptance of illness (including pain associated with it) greatly affects the patient's well-being, perception of illness-related symptoms, and even the occurrence of disability [5, 6].

Acceptance of illness is an emotional determinant of functioning with and adaptation to the illness and is manifested in a small intensity of negative emotions associated with the illness. Factors such as the course of illness, conditions

and treatment options, prognosis, as well as individual predispositions (emotions, coping with stress, etc.), directly affect the patient's attitude towards the illness, thus associating with the process of its acceptance. Greater acceptance of illness means better adaptation to it, a diminished sense of mental discomfort, and acceptance of the limitations associated with the illness. Patients who accept their illness react better to appearing symptoms much more mildly than those who have a low degree of acceptance of illness [7, 8]. Acceptance of illness allows the patient to function properly despite various risks, limitations and problems resulting from the loss of health. Awareness of the causes and effects of the illness, as well as the knowledge of possible complications, enable the patients to effectively self-control and use health-promoting behaviours in order to increase the quality of life and its prolongation.

Acceptance of illness, especially as serious and chronic as cancer, is characterized by individualized dynamics. The effects of low level of acceptance of illness are associated with

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anxiety, sense of threat, sadness, depressed mood, irritability and sensitivity [8].

An illness, especially cancer, triggers negative emotions such as anger, a sense of threat, fear, anxiety and even depression. This affects the level of acceptance of the illness, and thus may prevent restoration of physical and mental health. Cancer constitutes a heterogeneous group of diseases in terms of the clinical image, which is associated with different prognosis. Malignant cancer is the second cause of death in Poland, causing 27.3% of deaths among men and almost 24.1% of deaths among women in 2016. Malignant cancer is a significant health problem, especially for young and middle-aged people (25–64 years). It is particularly observed in the female population – cancers before the age of 65 have been the most frequent cause of death for several years and account for 32% of deaths among young women and 49% of middle-aged women. In 2016, information on over 164,000 new incidents and almost 100,000 deaths due to cancer was submitted to the National Cancer Registry [9].

Adaptation to cancer is a problem of coping with the illness itself and its immediate consequences, such as pain or malaise. In the long-term perspective, it is necessary to cope with changes in the quality of life caused by the illness [10]. Therefore, it requires acceptance of new circumstances related to the illness and changes that have occurred in the personal and socio-professional areas [11].

Acceptance of illness is measured using the Acceptance of Illness Scale (AIS) developed in 1984 by B. J. Felton, T. A. Revensson and G. A. Hinrichsen, and adapted to Polish conditions by Z. Juczyński. The AIS scale contains eight statements describing negative consequences of poor health in the assessment of limitations imposed by the illness, lack of self-sufficiency, a sense of dependence on others and reduced self-esteem. The general measure of the degree of acceptance of illness is the sum of the points received for all statements. A low score means no acceptance and adaptation to the illness and a strong sense of psychological discomfort; a high score indicates acceptance of one's medical condition and is manifested by the lack of negative emotions associated with the illness [11, 12].

The objective of the study is to normalize the AIS questionnaire for cancer patients.

## MATERIALS AND METHOD

**Characteristics of the studied normalization group.** The study covered 1,187 cancer patients aged 21–96 ( $M=62.12$ ;  $SD=14.03$ ), including 666 women aged 21–96 ( $M=58.17$ ;  $SD=12.88$ ) and 521 men aged 22–96 ( $M=67.12$ ;  $SD=13.75$ ). The criteria for enrollment was the patient's availability at the Maria Skłodowska-Curie Institute – Oncology Centre in Warsaw during conducting the study and the patient's consent for participation.

The structure of diagnosis in the study group was as follows:  
– women: breast cancer 29%, ovarian cancer 25.8%, endometrial cancer 17.4%, colorectal cancer 14.9%, stomach cancer 6.8%, pancreatic cancer 3.6%, bladder cancer 2.6%;  
– men: prostate cancer 43.8%, colorectal cancer 26.9%, bladder cancer 15.9%, stomach cancer 9.2%, pancreatic cancer 4.2% (Tab. 1).

Detailed information about the sample is presented in Table 2.

**Table 1.** Types of cancer in the sample and in the population

Cancer location	Women			Men		
	popu- lation (%)	sample (%)	weight	popu- lation (%)	sample (%)	weight
breast cancer	21.9	29.0	0.76	0	0	-
ovarian cancer	4.7	25.8	0.18	0	0	-
stomach cancer	2.4	6.8	0.35	4.5	9.2	0.49
colorectal cancer	10.1	14.9	0.68	12.2	26.9	0.45
prostate cancer	0	0	-	15.5	43.8	0.35
bladder cancer	2.0	2.6	0.77	6.9	15.9	0.43
endometrial cancer	7.3	17.4	0.42	0	0	-
pancreatic cancer	2.2	3.6	0.61	2.3	4.2	0.55

**Table 2.** Characteristics of the studied normalization sample

Characteristic	<i>n</i>	%
Age		
20–40	94	7.9
40–65	574	48.5
65+	516	43.5
missing value	3	.3
Education		
primary	97	8.3
vocational	250	21.1
secondary	447	37.7
higher	393	33.1
Place of residence		
Village	221	18.6
City up to 20,000 residents	131	11.0
City up to 50,000 residents	154	13.0
City up to 100,000 residents	144	12.1
City up to 500,000 residents	110	9.3
City above 500,000 residents	427	36.0
Average monthly income		
no data	8	0.7
below 500 PLN	24	2.0
501–1,000 PLN	210	17.7
1,001–1,500 PLN	317	26.7
1,501–2,000 PLN	299	25.2
Above 2,000 PLN	329	27.7
Professional status		
Working	464	39.1
Student	19	1.6
Retired/pensioner	618	52.1
Homemaker	53	4.5
Unemployed	33	2.8
Marital status		
Unmarried	93	7.8
Married	812	68.4
Widow/widower	192	16.2
Divorced	90	7.6
<b>Total</b>	<b>1,187</b>	<b>100</b>

**Tool used in the study.** The AIS is intended for the examination of adults who are currently ill. All patients gave informed consent to participate in the study. The AIS scale consists of 8 statements describing consequences of poor health in the assessment of limitations imposed by the illness, lack of self-sufficiency, a sense of dependence on others, and reduced self-esteem. In each statement, the examined patient determines his/her current state at a 5-degree scale, from 1 – strongly agree, to 5 – strongly disagree. Strong agreement (score 1) expresses poor adaptation to the illness, while a strong disagreement (score 5) means acceptance of illness. The general measure of acceptance of illness is the sum of all points, and its range is in the area of 8–40 points. A low score means no acceptance and adaptation to the illness and a strong sense of mental discomfort, a high score indicates acceptance of one's medical condition and is manifested by the lack of negative emotions associated with the illness.

Reliability of the Polish version of the AIS scale is similar to the reliability of the original version, where the Cronbach's alpha coefficient is 0.82, and the test-retest consistency indicator over 7 months is 0.69 [13].

## RESULTS

Calculations were performed with the use of IBM SPSS Statistics 25.0 software. Table 3 presents descriptive statistics for the level of acceptance of illness depending on demographic variables together with values of tests concerning the significance of statistical differences. Based on the value of the Kolmogorov-Smirnov test [14], it was found that the distribution of the level of acceptance in the study sample significantly differed from the normal distribution,  $Z=1.46$ ,  $p < 0.05$ . The measure of skewness was equal to  $S=-.28$ ,  $z=-2.72$ ;  $p < .05$ . The measure of kurtosis was equal to  $K=-.82$ ,  $z=-3.93$ ;  $p < .001$ . Both statistically significant were

**Table 3.** Descriptive statistics for the level of acceptance of illness depending on demographic variables

		M	SD	min	max	Test	p
Gender	women	27.15	8.05	8	40	$U=2808.50$	0.067
	men	28.36	8.24	8	40		
Education	primary/ vocational	26.01	8.39	8	40	$\chi^2(2)=9.34$	0.009
	secondary	27.85	7.89	8	40		
	higher	28.76	8.02	8	40		
City/town size	up to 100,000 residents	26.57	8.30	8	40	$U=11902.00$	0.001
	above 100,000 residents	28.89	7.77	8	40		
Net income	up to 1,500 PLN	26.07	8.09	8	40	$U=12022.50$	0.001
	above 1,500 PLN	29.07	7.92	8	40		
Professional status	Working person	28.58	7.53	8	40	$U=11132.00$	0.036
	Student	21.24	7.89	12	39		
	Retired/pensioner	27.24	8.52	8	40		
	Homemaker	27.18	7.83	11	40		
	Unemployed	24.96	7.98	11	40		
	Total	27.62	8.14	8	40		

M – median; SD – standard deviation; min – minimum value; max – maximum value; U – Mann-Whitney's test value;  $\chi^2$  – H Kruskal-Wallis test value; p – statistical significance.

**Table 4.** Descriptive statistics for level of acceptance of illness depending on the illness indicators.

		M	SD	min	max	U	p
Metastases	yes	25.21	7.86	8	40	7,832.50	0.001
	no	28.77	8.00	8	40		
Chemotherapy	yes	26.07	7.78	8	40	11,853.50	0.005
	no	28.51	8.21	8	40		
Radiotherapy	yes	26.31	7.81	10	40	7,071.00	0.237
	no	27.82	8.18	8	40		
Targeted therapy	yes	25.58	7.42	10	40	3,950.00	0.228
	no	27.78	8.18	8	40		

M – median; SD – standard deviation; min – minimum value; max – maximum value; U – Mann-Whitney test value; p – statistical significance

different from zero. Therefore, non-parametric statistical significance tests were used concerning education, place of residence, income and professional status [15]. Data were verified for possible outliers with the use of boxplot chart, but none were detected.

Acceptance of illness was the lowest in the group of people with primary or vocational education ( $M=26.10$ ), compared to those with secondary ( $M=27.93$ ) and higher education ( $M=28.73$ ); it was lower in the group of people living in smaller towns ( $M=26.60$ ), compared to those living in larger cities ( $M=28.94$ ); it was lower in the group of people with monthly net income per one person in the family below PLN 1,500 ( $M=26.15$ ), compared to those with higher earnings ( $M=29.07$ ), and lower in the group of retirees or pensioners ( $M=27.24$ ) than in the group of working people ( $M=28.58$ ). However, no statistically significant gender differences were found; therefore, the norms were set for the whole sample under consideration. Based on the value of Spearman's r correlation coefficient, there was no statistically significant correlation between the acceptance of illness and age of the respondents –  $r=0.04$ ;  $p > 0.05$ .

Table 4 presents descriptive statistics for the level of acceptance of illness depending on the illness indicators, together with the values of the U Mann-Whitney's test, indicating that the acceptance of illness was lower among people with metastases and among people during chemotherapy treatment.

**Norms.** Table 5 presents the values of sten and percentile norms determined in the study sample using the calculated weight. Results on the sten scale from 1–3 sten should be interpreted as low, from 4–7 sten – as average, and from 8–10 sten – as high, compared to the population of people diagnosed with cancer.

## DISCUSSION

Acceptance of illness is one of the important factors affecting the quality of life of patients with chronic diseases. Cancer affects all aspects of human functioning, both the physical sphere and the psychosocial and spiritual areas, whereby changes related to adaptation to the new conditions determined by the illness may be difficult for patients. Acceptance of illness creates a sense of security, reduces the severity of negative reactions and emotions associated with the illness, thereby reducing the feeling of mental discomfort.

**Table 5.** Raw results and corresponding normalized results

Results	Value	Sten	Centile	
low	8	1	1	
	9	1	1	
	10	1	1	
	11	1	2	
	12	2	3	
	13	2	4	
	14	2	6	
	15	3	8	
	16	3	10	
	17	3	13	
	18	3	15	
	average	19	4	17
		20	4	20
		21	4	23
		22	4	26
		23	4	29
		24	5	33
		25	5	38
26		5	42	
27		5	45	
28		5	49	
29		6	53	
30		6	57	
31		6	62	
32		6	66	
33		7	70	
34		7	75	
35		7	78	
36		7	82	
high	37	8	85	
	38	8	88	
	39	8	91	
	40	9	96	

Assessment of the quality of life of oncological patients is an important aspect of the therapeutic process. Diagnosis of cancer is associated with the strong emotional reactions of each patient, and this reaction is dependent on individual personality traits and mechanisms responsible for coping in stressful situations. Attitude towards the illness affects the treatment process, and the level of acceptance of illness determines the patient's well-being, the level of confidence in medical staff and treatment methods, and hence, also the success of the therapy [16], which indicates the need to assess the acceptance of illness in patients. Differences in the acceptance of illness between patients with oncological and non-oncological illnesses are indicated by Dryhinicz M et al., stressing that oncological patients achieve lower AIS results ( $M=20.68$ ,  $SD=8.74$ ) than non-oncological patients ( $M=32.22$ ;  $9.44$ ) [8].

In the current study, normalizing the AIS questionnaire, conducted among cancer patients, the average acceptance of illness for women was  $M=27.15$  ( $SD=8.05$ ), and for men  $M=28.36$  ( $SD=8.24$ ), which is comparable with the study

conducted by Koziel P. et al. among women with breast cancer, where the average acceptance of illness was  $M=27.21$  ( $SD=8.96$ ) [16]. The study by Cipora E et al., covered a group of 231 women who received treatment for breast cancer which indicated that the mean level of acceptance of the illness in the examined group of women was 26.53 ( $SD = 7.71$ ) [17].

The overall illness acceptance rate in the study group of cancer patients in the current study was slightly lower for women than the results obtained by Z. Juczyński for patients treated for breast and uterine cancer ( $M=28.13$ ,  $SD=7.60$ ), but higher for both women and men in the current study than for other groups of patients in the study of Z. Juczyński, among patients treated for diabetes ( $M=24.81$ ,  $SD=7.09$ ) and patients with multiple sclerosis ( $M=24.59$ ,  $SD=7.20$ ) [12].

In the study conducted by Z. Juczyński, who adapted the AIS questionnaire for Polish conditions, the lowest average illness acceptance rate was obtained by patients treated for chronic pain ( $M=18.46$ ,  $SD=7.05$ ) and patients with spinal pain ( $M=20.51$ ,  $SD=8.74$ ). The authors of the AIS questionnaire, B.J. Felton and T.A. Revensson in two different studies among 151 chronic patients (hypertension, diabetes, arthritis, cancer) obtained results similar to those obtained in the current study, where the mean values were:  $M=28.08$  ( $SD=5.60$ ) and  $M=28.48$  ( $SD=5.92$ ) [12, 18].

The AIS questionnaire was used to assess the acceptance of illness by patients with leukemia, where the average acceptance of illness was  $M=23.27$  ( $SD=9.06$ ) [11]. In the case of women with cervical cancer, the level of acceptance of illness was  $M=28.76$  [19]. Among patients with Parkinson's disease, the average acceptance of illness was  $M=25.28$  ( $SD=7.26$ ), among patients on dialysis –  $M=25.68$  ( $SD=9.35$ ), among patients with psoriasis –  $M=27.46$  ( $SD=8.58$ ), and among patients with multiple sclerosis, the AIS test result was  $M=24.83$  ( $SD=9.41$ ) [20, 21, 22]. A significantly higher average level of acceptance of illness characterizes diabetic patients, which in the studies conducted by Krupas D. et al. was  $M=29.00$ , and in the study conducted by Starczewska M. et al. –  $M=31.80$  ( $SD=7.91$ ) [13, 23].

Acceptance of illness is very important in the treatment of patients with chronic diseases, significantly affecting the prognosis of patients [7, 20, 24, 25, 26]. Studies show that patients with better acceptance of illness care much more about their health, control their test results and follow the recommendations better [18, 27]. Research also confirms that greater acceptance of the disease is associated with lower negative emotions and a higher level of motivation to undertake and continue treatment by the patient [28]. The results of some studies indicate that the acceptance of illness increases with patients' age. Harrison T. et al. supposes that this happens because various dysfunctions of the body are more socially accepted in the elderly [27]. Sceinti E. et al. also indicate that the level of acceptance of illness is affected by marital status and stage of the cancer, which is also confirmed by studies conducted by other authors [4, 7].

Studies assessing the quality of life play an increasingly important role in decisions concerning patients' therapy; many doctors consider the impact of treatment on the quality of life of the patient, which may in turn affect the level of acceptance of illness. The assessment of the acceptance of illness among patients with chronic diseases, including cancer, should constitute an integral part of the therapeutic process, because actions to increase the level of acceptance of illness affect the minimization of negative feelings associated

with the illness, and thus more effective illness control and quality of life assessed better by the patients [4, 13, 20, 22].

## CONCLUSION

Normalization studies clearly indicate that the sten norms for the Acceptance of Illness Scale (AIS) developed by B. J. Felton, T. A. Revensson and G. A. Hinrichsen can be used among cancer patients. Results according to the AIS were differentiated by socio-economic as well as medical factors.

Assessment of the level of acceptance of illness among patients, as well as the attempt to find factors influencing the acceptance of illness, allow for appropriate treatment selection for individual patients, as well as for psychotherapeutic support of those patients whose level of acceptance of illness is the lowest.

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