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

Aleksandra Czerw1,2,A,C-F, Urszula Religioni1,3,A,C-E, Paweł Szumilas4,B-C, Katarzyna Sygit5,C-D, Olga Partyka3,D-E, Dominika Mękal3,4,A,C-D, Sylwia Jopek1,4,C-D, Marcin Mikos7,D-F, Łukasz Strzępek8,B-D

1 Department of Health Economics and Medical Law, Medical University of Warsaw, Warsaw, Poland
2 Department of Economic and System Analyses, National Institute of Public Health NIH-National Research Institute, Warsaw, Poland
3 Collegium of Business Administration, Warsaw School of Economics, Warsaw, Poland
4 Subdepartment of Social Medicine and Public Health, Department of Social Medicine, Pomeranian Medical University in Szczecin, Szczecin, Poland
5 Faculty of Health Sciences, Calisia University, Kalisz, Poland
6 Department of Cancer Prevention, Medical University of Warsaw, Warsaw, Poland
7 Faculty of Medicine and Health Sciences, Andrzej Frycz Modrzejewski Krakow University, Krakow, Poland
8 Department of General Surgery, Regional Public Hospital in Bochnia, Bochnia, Poland

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 Sklodowska-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...
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.

TABLE 2. 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.
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 $S = -0.28, z = -2.72, p < 0.05$. The measure of kurtosis was equal to $K = -0.82, z = -3.93, p < 0.001$. Both statistically significant were 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 3. Descriptive statistics for the level of acceptance of illness depending on demographic variables

| Category                      | 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 education  | 26.01 | 8.39 | 8 | 40 | c²=9.34     | 0.009 |
| secondary education           | 27.85 | 7.89 | 8 | 40 |           |       |
| higher education              | 28.76 | 8.02 | 8 | 40 |           |       |
| City/town                     |    |     |     |      |           |       |
| 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                           |    |     |     |      |           |       |
| 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 |
| Retired/pensioner             | 21.24 | 7.89 | 12 | 39 |           |       |
| Homemaker                     | 27.24 | 8.52 | 8 | 40 |           |       |
| Unemployed                    | 27.18 | 7.83 | 11 | 40 |           |       |
| Total                         | 24.96 | 7.98 | 11 | 40 |           |       |
| M – median; SD – standard deviation; min – minimum value; max – maximum value; U – Mann-Whitney’s test value; c² – H Kruskal-Wallis test value; p – statistical significance.

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

| Illness Indicator | M  | SD  | min | max  | U   | p     |
|-------------------|----|-----|-----|------|-----|-------|
| Metastases        | 25.21 | 7.86 | 8 | 40 | 7,832.50 | 0.001 |
| Chemotherapy      | 28.77 | 8.00 | 8 | 40 |           |       |
| Radiotherapy      | 26.07 | 7.78 | 8 | 40 | 11,853.50 | 0.005 |
| Targeted therapy  | 28.51 | 8.21 | 8 | 40 |           |       |
| M – median; SD – standard deviation; min – minimum value; max – maximum value; U – Mann-Whitney test value; p – statistical significance.

### Table 5. Sten and percentile norms for level of acceptance of illness.

| Norm | Sten | Percentile |
|------|------|------------|
| Min  | 4    | 20%        |
| Mid  | 6    | 50%        |
| Max  | 8    | 80%        |

M – median; SD – standard deviation; min – minimum value; max – maximum value; U – Mann-Whitney’s test value; p – statistical significance.
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 Dryhiniacz 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. Revesson 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. Revenson 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.

REFERENCES

1. Zyda D, Steele G, Gupta P. A systematic review of the impact of pain on overall survival in patients with cancer. Support Care Cancer. 2017; 25(5): 1687–1698. https://doi.org/10.1007/s00520-017-3614-y
2. Grassi L, Le Guillou E; Izadiar A, et al. Factors associated with poor acceptance of illness in patients with COPD. Rev Mal Respir. 2019; 36(4): 461–467. https://doi.org/10.1016/j.rmr.2018.11.010
3. Lauwerier E, Caes L, Van Damme S, et al. Acceptance: What’s in a name? A content analysis of acceptance instruments in individuals with chronic pain. J Pain. 2015; 16(4): 306–317. https://doi.org/10.1016/j.jpain.2015.01.001
4. Secinti E, Tometch DB, Johns SA, et al. The relationship between acceptance of cancer and distress: A meta-analytic review. Clyn Psychol Rev. 2019; 71: 27–38. https://doi.org/10.1016/j.cpr.2019.05.001
5. Chabowski M, Polański J, Jankowska-Polanska B, et al. The acceptance of illness, the intensity of pain and the quality of life in patients with lung cancer. J Thorac Dis. 2017; 9(9): 2952–2958. https://doi.org/10.21037/jtd.2017.08.70
6. Gillaunders ST, Ferrera NB, Bose S, et al. The relationship between acceptance, catastrophizing and illness representations in chronic pain. Eur J Pain. 2017; 17(6): 893–902. https://doi.org/10.1002/ejp.20132-2149.2012.00248.x
7. Uchmanowicz I, Pieniacka M, Kuśnierz M, et al. Acceptance of illness and quality of life in heart failure. Probl Pneumol. 2015; 23(1): 69–74. https://doi.org/10.5603/PP.2015.0012
8. Dryhymincz M, Rzepa T. The level of anxiety, acceptance of disease and the strategy of coping with stress in patients oncological and non-oncological. Ann UMCS Sec J. 2018; 31(1): 7–20. https://doi.org/10.17951/j.2018.31.1.7-21
9. Wojciechowska U, Czaderny K, Ciuba A, et al. Malignancies in Poland in 2016, Center of Oncology – Maria Skłodowska-Curie Institute. Warsaw 2018. http://onkologia.org.pl/wpcontent/uploads/Nowotwory_2016.pdf (accessed 27 July 2019).
10. Juczyński Z, Chrystowska-Jabłońska B. Strategia radzenia sobie z chorobą nowotworową [Strategy for coping with cancer]. Psychoonkologia. 1999; 5: 3–9.
11. Wiraśka G, Leonak B. The Functioning of a patient with leukaemia and the acceptance of neoplastic disease. Stud Med. 2008; 10: 21–26.
12. Juczyński Z. Measurement tools in health promotion and psychology. Warsaw: Laboratory of psychological tests; 2001. pp. 162–166.
13. Kurpas D, Czech T, Mrózek B. Illness acceptance in patients with diabetes and its influence on the quality of life and the subjective assessment of health. Fam Med Primary Care Rev. 2012; 14(3): 383–388.
14. Alan S, Keith O; Steven A, Kendall’s Advanced Theory of Statistics. T. 2A. London: Arnold, a member of the Hodder Headline Group; 1999. p. 25.37–25.43
15. Field A. Discovering Statistics Using IBM SPSS Statistics. Sage Publications. 2017.
16. Koziel P, Lomper K, Uchmanowicz B, et al. Association between acceptance of illness, anxiety and depression with assessment quality of life of breast cancer patients. Med Patial Prakt. 2016; 10(1): 28–36.
17. Cipora E, Konieczny M, Sobieszczański J. Acceptance of illness by women with breast cancer. Ann Agric Environ Med. 2018; 25(10): 167–171. https://doi.org/10.26444/aaem/75876
18. Felton BJ, Revenson TA. Coping with chronic illness: a study of illness controllability and the influence of coping strategies on psychological adjustment. J Consult Clin Psychol. 1984; 52(3): 343–353. https://doi.org/10.1037/0022-006x.52.3.343
19. Kazmierczak M, Kubiak I, Gebuza G, et al. Czynniki determinujące akceptację choreby przez kobiety leczone z powodzeniem patologicznych szczytów macicy [Factors determining the acceptance of illness by women treated for pathological changes in the cervix], Med Og Nauk Zdr. 2015; 21(2): 181–186. https://doi.org/10.5604/20834343.1152917
20. Rosińczuk J, Kołtuniuk A. The influence of depression, level of functioning in everyday life, and illness acceptance on quality of life in patients with Parkinson’s disease: a preliminary study. Neuropsychiatr Dis Treat. 2017; 13: 881–887. https://doi.org/10.2147/NIT.S132757
21. Basińska MA, Waraska-Wisniewska M, Andruszkiewicz A. Mood as acceptance of illness determinant of diahytis patients. Nefro Diap Pol. 2014; 18: 27–31.
22. Rosińczuk J, Rychła K, Bronowicka I, et al. The Impact of Illness Acceptance on Quality of Life of Patients with Multiple Sclerosis – Preliminary Study. JNNN. 2017; 6(4): 157–162. https://doi.org/10.15225/JPNN.2017.6.4.4
23. Starczewska M, Kujawska R, Stanisławska M, et al. The analysis of health behaviors and illness acceptance in patients with diabetes. Fam Med Prim Care Rev. 2018; 20(4): 352–355. https://doi.org/10.5114/fmcr.2018.79347
24. Obieglo M, Uchmanowicz I, Wleklik M, et al. The effect of acceptance of illness on the quality of life in patients with chronic heart failure. Eur J Cardiovasc Nurs. 2016; 15: 241–247. https://doi.org/10.1177/1474515114564929
25. Jankowska-Polańska B, Iloko A, Wleklik M. Wpływ akceptacji choroby na jakość życia chorecych z nadszczepieniem tętniczym [The influence of acceptance of illness on the quality of life of patients with hypertension]. Nácisń Tętn. 2014; 18: 143–150.
26. Olek D, Uchmanowicz I, Chudnik A, et al. Wpływ akceptacji choroby na jakość życia chorecych w przewlekłej obstrucjnej chorobie pluc [The influence of acceptance of illness on the quality of life of patients with chronic obstructive pulmonary disease]. Probl Pneumol. 2014; 22: 471–476.
27. Harrison T, Stuifbergen A, Adachi E, et al. Marriage, impairment and acceptance in persons with multiple sclerosis. West J Nurs Res. 2004; 26: 266–285. https://doi.org/10.1177/1048684403260188
28. Leong WC, Azmi NA, Wee LH, et al. Validation and reliability of the Bahasa Malaysia language version of the Acceptance of Illness Scale among Malaysian patients with cancer. PLOS ONE 2021; https://doi.org/10.1371/journal.pone.0256216