Prevalence and Determinants of Psychological Distress in Adolescent and Young Adult Patients with Cancer: A Multicenter Survey

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ABSTRACT

Objective: This study aimed to investigate the current prevalence and determinants of psychological distress and the association of distress with general information, character strengths, medical coping, and social support in Chinese adolescents and young adults (AYAs) aged 15–39 years with cancer. **Methods:** A multicenter survey was carried out. Eight hundred and nine patients completed the Chinese version of the National Comprehensive Cancer Network distress thermometer (DT), the three-dimensional inventory of character strengths, the medical coping modes questionnaire, and the Social Support Rating Scale. **Results:** The current prevalence of psychological distress in Chinese AYAs with cancer was 83.4%. Binary logistic regression analysis showed that gender, age, educational level, marriage, monthly income, exercise intensity, cancer classifications, treatments, self-control, confrontation, avoidance, and subjective support were all associated with distress. AYA cancer patients who were female, younger, or divorced or had a lower monthly income, education level, or exercise intensity were more likely to have higher level of distress. Compared to AYAs with other cancer classifications, patients with digestive system malignancies, breast cancers, and head and neck malignancies had a higher prevalence of distress. Patients receiving chemotherapy or radiotherapy were more likely to be distressed. The higher the self-control, confrontation, avoidance, and subjective support scores were, the lower the prevalence of distress was among AYA cancer patients. **Conclusions:** The prevalence of psychological distress in AYA cancer patients was relatively high. Potential interventions targeting exercise intensity, character strengths, medical coping, and social support may decrease the prevalence of psychological distress in this patient population.

Key words: Adolescent and young adult, cancer, character strengths, distress, medical coping, social support

Introduction

At present, the prevalence of adolescent and young adults (AYA) aged 15–39 years with cancer is quickly increasing. Studies have shown that the prevalence of cancer in AYAs is 164.2/1,000,000.[1] In China, the crude cancer prevalence was reported to be approximately 87.56 per million person-years among AYAs.[2] Cancer is the leading cause of disease-related deaths in AYAs,[3] accounting for nearly 40% of the total disease-related deaths in China.[4] Cancer not only damages patients' physical health but also affects their mental health. A study conducted in China showed that approximately 30% of cancer patients experienced psychological distress.[5] The prevalence of psychological distress among AYA cancer patients was higher than that of the general cancer population, with an increased risk during the first year after the diagnosis.[6,7]

At present, increasing attention has been given to the psychological distress of AYA cancer patients, and many studies have explored its influencing factors. There is a significant association between pain and psychological stress in adult cancer patients.[8,9] In China, studies have shown that 31.2% of 846 cancer patients were found to have significant PTSD symptoms. Significant symptoms of depression, anxiety, and distress were present in 13.9%, 15.1%, and 25.3% of patients, respectively. Women more often reported symptoms of PTSD, anxiety, and distress.[10] Significant distress among AYAs with cancer varies, ranging from 6% to 89% in independent cross-sectional studies with varying sample sizes, age ranges, timing of data collection, and the tools utilized.[6,7] For AYAs, in addition to physical pain, the social impact of cancer can also cause psychological distress.[11] The AYA Oncology Progress Review Group of the USA published its findings on AYAs with cancer, showing they experienced significant disruptions in their education and they felt isolated from friends and social groups.[12] Despite therapeutic advances, the AYA population has derived less incremental benefit compared to both pediatric and adults with cancer.[13]

AYAs have unique oncology and needs, which distinguish them from other age groups because their unique psychosocial and emotional needs run through the cancer trajectory, and we need to pay attention to the care they receive during diagnosis and survival.[14,15] AYA patients reported greater emotional distress, not only immediately after treatment but also many years after treatment compared to their peers and older survivors. Moreover, one study found that the effects of late-stage cancer treatment in patients were largely due to psychological care received during childhood and adolescence. Multiple symptoms associated with their cancer and its treatment can have a negative impact on the development and quality of life of AYAs.[16] In addition, AYAs are faced with the challenge of a shortage of resources in the area of medical/disease due to limited resources for medical coping and mental health, as well as additional resources for major health-related events.[17,18] A great majority of AYA cancer patients reported that one of the cancer's greatest challenges was dealing with the emotional impacts of cancer on family members and their medical coping.[19] Therefore, the psychological care and medical coping of young cancer patients deserves more attention.[6,14]

Moreover, cancer may interfere with the realization of character strengths, which are critical to the establishment of self-esteem and the management of disease-related challenges and the relationships between family and society.[6,20] Positive psychology and character strengths theory are psychological theories developed in the 21st century, suggesting that these aspects play an important role in developing one's own potential, promoting positive emotional experiences and maintaining a good psychological state. Researchers have produced a classification of character strengths, the Values-in-Action Classification of Character Strengths.[21,22] Studies have demonstrated that character strengths have an indirect effect on depression through the mediation of dysfunctional attitudes, negative affect, and happiness. They also illustrated that character strengths had negative effects on dysfunctional attitudes and positive effects on happiness.[23,24] One study showed that character strengths are stress defense factors that allow for psychological and physiological adaptation to stress by young adults.[25] These findings have implications for practitioners and researchers in focusing on the influence of AYA character strengths on the treatment of psychological distress. Some studies have shown that the character strengths of Cambodian college students are honesty, kindness, fairness, teamwork, and leadership. Hope and gratitude have great advantages in reducing psychological distress among students, and a corresponding intervention is needed.[26] Character strengths and virtues play an independent role in regulating Coronavirus Disease 2019 (COVID-19)-related stress and well-being. Higher levels of character strengths significantly and independently moderated the relationship between COVID-19-related stress and well-being.[27]

AYAs also face unique repercussions from cancer on their familial and social relationships. Regarding family relationships, the authors stress that AYA cancer patients face unique challenges that may stem from conflicting needs of support and autonomy.[19] Medical coping and social support can reduce the prevalence of psychological distress in AYA patients with cancer.[19] There is also evidence of the importance of social welfare in the quality of life of

the survivors. When they leave the care of their families and live independently, they will need more support and help from society.[28] They may also feel guilty and anxious as they try to gain autonomy and witness the pain of their family members, since nothing can alleviate the pain of their family.[19,29]

Currently, there are few cross-sectional studies on AYA cancer patients with large sample sizes in China, so we do not understand their prevalence, nor have we systematically investigated their character strengths, medical coping and social support and the direct relationship among them, which is the gap we found. This study investigated the psychological distress of 809 cancer patients in Changsha, aiming to understand the current situation and influencing factors of the psychological distress of AYA cancer patients in China and to provide a reference for further improving the mental health of AYA cancer patients.

Methods

Participants

To reflect the prevalence of cancers in China, 1000 AYA cancer patients were recruited from among inpatients hospitalized at Hunan Cancer Hospital, Xiangya Hospital, Second Xiangya Hospital, and Third Xiangya Hospital of Central South University (Hunan, China) between March and October 2018.

Among the 1,000 patients, there were 125 patients with digestive system cancers, 125 patients with hematological cancers, 125 patients with gynecological cancers, 125 patients with lung cancers, 125 patients with breast cancers, 125 patients with head and neck cancers, 125 patients with skin cancers, and 125 patients with other malignancies. The inclusion criteria were (1) 15 to 39 years of age, (2) hospitalization, (3) a diagnosis of cancer, and (4) no history of mental illness before the diagnosis of cancer. The exclusion criteria were (1) mentally unstable or major mental disorder and (2) communication disorder or excessive dependence on medicine or alcohol.

Methods

Instruments

A 13-item general data questionnaire was used to collect participants' gender, age, living circumstance, educational level, marital status, monthly income, exercise (including exercise intensity and frequency), cancer classifications, diagnosis time, treatments, other diseases, medical insurance, and psychiatric family history.

Distress thermometer

The distress thermometer (DT) was proposed by the National Comprehensive Cancer Network. The validated Chinese version of the DT was adapted to assess the level of distress on a scale ranging from 0 (no distress) to 10 (extreme distress) for this study. The Chinese version of the DT was initially developed to evaluate prostate cancer patients and subsequently validated in other cancer populations. Using a cut off score of 4, the sensitivity value was 0.82 and the specificity value was 0.95 in Chinese cancer patients.[30] In addition, the sources of distress, including emotional, family, physical, practical, and spiritual distress, were self-reported using a published problem list.

Three-dimensional inventory of character strengths

The three-dimensional inventory of character strengths (TICS) is a 15-item scale for measuring three character strengths (caring, inquisitiveness, and self-control).[31] There are 5 items in each subscale. Participants were required to rate each item from 1 (very much unlike me) to 5 (very much like me). The total score of each subscale was obtained by summing the score of each item on the subscale. The good internal reliabilities (Cronbach's α higher than 0.74) and predictive validities of all subscales were confirmed in a cross-population (community participants vs. inpatients) sample and a cross-cultural (Asians vs. Westerners) sample.[32]

Medical coping modes questionnaire

The Chinese version of the medical coping modes questionnaire (MCMQ) was used to measure medical coping. The MCMQ has 20 items in total and it contains 3 dimensions: confrontation (8 items), avoidance (7 items), and acceptance (5 items). Among the 20 items, the scores of 12 items ranged from 1 (never) to 4 (often), and the scores of 8 items were inverted from 1 (often) to 4 (never). The total scores of the subscales are calculated, with higher scores indicating increased use of each coping strategy. Each subscale has good internal reliability and predictive validity in different types of patients.[33]

Social Support Rating Scale

The Social Support Scale (SSRS)[34] is an instrument widely used in the evaluation of social support of Chinese cancer patients. The SSRS consists of 10 items, which are divided into three subscales: objective support (3 items), subjective support (4 items), and support utilization (3 items). Items were mostly scored on a 4-point Likert scale (excluding questions about the "sources of support"), ranging from "never seek help from others" (1) to "actively seek help from others" (4). The total score ranges from 11 to 62, with a higher score indicating better social support. The reliability and validity of the scale are acceptable.[35,36]

Procedure

The study team consisted of 1 chief nurse, 2 associate chief nurses, 6 nursing postgraduates, and 1 investigation

secretary. Participants signed the written informed consent form under the guidance of team members after an explanation of the study's purpose. All questionnaires were completed anonymously by the participants themselves without any interference. To increase the accuracy of the survey, participants were given 30–45 min to complete the survey.

Statistical analysis

All information from the questionnaires was entered into a computer according to serial numbers on the questionnaires. The data were analyzed using SPSS 23.0 software. Descriptive statistics were conducted to describe the characteristics of the participants and the DT, TICS, MCMQ, and SSRS scores. A forward stepwise binary logistic regression analysis was conducted to explore the influence of general information, the three character strengths, medical coping and social support on psychological distress (α_{in} = 0.05, α_{out} = 0.10). $P < 0.05$ was considered statistically significant.

Results

Characteristics of the participants

A total of 1000 questionnaires were sent out, and 809 were filled out and found to be valid (80.90%). The majority of participants were between 36 and 39 years old (48.8%) and married (72.7%). Other characteristics of the participants are shown in Table 1.

Scores of DT, TICS, MCMQ, and SSRS among AYA cancer patients

Scores on the DT exhibited an approximately normal distribution, with 6 being the most common score (35.6%). A score of 4 or higher was used as a cutoff score of distress. The prevalence of psychological distress in AYAs with cancer was 83.4%. The average scores for the character strengths, medical coping, and social support are shown in Table 2.

Factors associated with distress among adolescent and young adult cancer patients

Binary logistic regression analysis showed that gender, age, educational level, marriage, monthly income, exercise intensity, cancer classifications, treatments, self-control, confrontation, avoidance, and subjective support were all associated with distress [Table 3]. A higher prevalence of distress was observed among AYA cancer patients who were female or divorced and who had digestive system malignancies, breast cancers, and head and neck malignancies. Age (odds ratio [OR] = 0.69), monthly income (OR = 0.50), education level (OR = 0.63), and

Table 1: Characteristics of the adolescents and young adults cancer patients (*n*=809)	
Characteristics	***n* (%)**
Gender	
Male	326 (40.3)
Female	483 (59.7)
Age (years)	
15-20	39 (4.8)
21-25	113 (14.0)
26-30	143 (17.7)
31-35	119 (14.7)
36-39	395 (48.8)
Living circumstance	
Urban area	224 (27.7)
County area	188 (23.2)
Town area	150 (18.5)
Rural area	247 (30.5)
Educational level	
Elementary school and below	99 (12.2)
Middle school	138 (17.1)
High school	191 (23.6)
College	341 (42.2)
Beyond college	40 (4.9)
Marriage	
Single	193 (23.9)
Married	588 (72.7)
Widowed/divorced	28 (3.5)
Monthly income (RMB)	
>5000	126 (15.6)
3000-5000	406 (50.2)
1000-3000	152 (18.8)
500-1000	69 (8.5)
<500	56 (6.9)
Exercise intensity	
No exercise	198 (24.5)
Light (exercise, qigong, tai chi, walking, etc.)	434 (53.6)
Moderate (swimming, cycling, brisk walking/jogging, dancing, golf, sit-ups, etc.)	122 (15.1)
Vigorous (mountain climbing, jumping, weightlifting, etc.)	55 (6.8)
Exercise frequency per week (times)*	
<3	331 (40.9)
≥3	124 (15.3)
Irregularity	156 (19.3)
Cancer classifications	
Digestive system malignancies	105 (13.0)
Hematological malignancies	96 (11.9)
Gynecologic malignancies	93 (11.5)
Lung cancers	103 (12.7)
Breast cancers	106 (13.1)
Head and neck malignancies	105 (13.0)
Skin cancers	101 (12.5)
Others	100 (12.4)
Diagnosis time	
<3 months	247 (30.5)
3-6 months	181 (22.4)
6-12 months	163 (20.1)
1-3 years	157 (19.4)

Contd...

Table 1: Contd...	
Characteristics	***n* (%)**
>3 years	61 (7.5)
Treatments	
Surgery	313 (38.7)
Chemotherapy/radiotherapy	154 (19.0)
Surgery + chemotherapy/radiotherapy	342 (42.3)
Accompanied by other diseases	
Yes	408 (50.4)
No	401 (49.6)
Medical insurance	
No medical insurance	50 (6.2)
Province and city level medical insurance	450 (55.6)
NCMS	292 (36.1)
Other medical insurance	17 (2.1)
Psychiatric family history (close blood relatives)	
Yes	37 (4.6)
No	772 (95.4)

*The total number of participants was 611 who have habitual exercises. NCMS: New Rural Cooperative Medical System

Table 2: Scores of distress Thermometer, Three-dimensional Inventory of Character Strengths, Medical Coping Modes Questionnaire, and Social Support Rating Scale among adolescents and young adults cancer patients (*n*=809)

Variables	Possible score range	Actual score range	Scores
DT	0-10	0-10	5.21±1.92
TICS-C	5-25	7-25	16.86±4.39
TICS-I	5-25	5-25	14.22±3.69
TICS-SC	5-25	6-25	16.29±4.97
MCMQ-C	8-32	9-32	18.93±6.16
MCMQ-Av	7-28	7-28	16.52±4.53
MCMQ-Ac	5-20	5-20	9.09±3.37
SSRS	11-62	22-60	42.52±6.26
SSRS-Os	7-28	12-29	24.46±3.86
SSRS-Ss	1-22	1-20	10.94±3.33
SSRS-Su	3-12	3-12	7.11±2.08

DT: Distress thermometer, TICS: Three-dimensional Inventory of Character Strengths, TICS-C: Caring subtotal score of TICS, TICS-I: Inquisitiveness subtotal score of TICS, TICS-SC: Self-control subtotal score of TICS, FS: Flourishing scale, MCMQ: Medical Coping Modes Questionnaire, MCMQ-C: Confrontation subtotal score of MCMQ, MCMQ-Av: Avoidance subtotal score of MCMQ, MCMQ-Ac: Acceptance subtotal score of MCMQ, SSRS: Social Support Rating Scale, SSRS-Os: SSRS-Objective Support, SSRS-Ss: SSRS-Subjective Support, SSRS-Su: SSRS-Support Utilization

exercise intensity (OR = 0.31) were protective factors. Patients receiving chemotherapy or radiotherapy (OR = 0.55) were more likely to be distressed. Higher scores of self-control (OR = 0.85), confrontation (OR = 0.85), avoidance (OR = 0.85), and subjective support (OR = 0.85) and a lower prevalence of distress were observed among AYA cancer patients.

Discussion

In this study, we investigated the prevalence of distress among AYA cancer patients and explored its associated factors. These results can not only provide a view of the distress among AYA cancer patients in a non-Western context but also provide implications for further intervention studies.

One of the main results we found in this study was that the prevalence of distress in AYA cancer patients was high (83.4%), higher than in the general cancer population.[8,37] Compared to the studies conducted among AYA cancer patients in other counties,[38,39] the prevalence of distress in this study was also higher. This may be due to different populations being recruited from different cultural backgrounds.

Binary logistic regression analysis indicated that distress was associated with the AYAs' demographic characteristics (gender, age, marriage, monthly income, and education level) and clinical characteristics (cancer classifications and cancer treatment). The results showed that AYA cancer patients who were female, younger, divorced and had lower monthly incomes and education levels seemed more likely to suffer from psychological distress. This suggests that we need to pay more attention to this group. For younger AYAs, their body and mind are still growing and developing, and they might have special needs and challenges in fertility preservation, parenting, schooling, and employment compared to patients of other ages. Therefore, we need to pay much more attention to distress among AYA cancer patients.

In addition, AYA cancer patients with lower educational levels were more likely to be distressed. This reveals that we need to consider the accessibility of the intervention measures and the patients' literacy level when delivering the interventions. Patients with a lower monthly income tended to have a higher level of distress because a lower income would affect their opportunity to live independently and reduce their productivity in the labor force.[40] Faced with the economic burden of cancer, AYA families are unlikely to pay attention to mental health because the cost of the treatment is their main concern. Therefore, there is more distress among low-income patients.

Compared to patients with other cancers, patients with digestive system malignancies, breast cancers or head and neck malignancies were more prone to psychological distress. This might be related to the fact that these cancers could damage the patients' appearance and influence interpersonal relationships. Among all cancer patients, breast cancer patients had the highest level of distress. Breast cancer patients accounted for 18.8% of AYAs in China.[41] Therefore, special attention should be paid to this population, and corresponding preventive measures should be taken.

Exercise intensity was also a protective factor associated with less distress. This could be explained from the

Table 3: Factors associated with distress among adolescents and young adults cancer patients

Variables	*B*	SE	Wals	df	*P*	OR	95% CI
Gender	0.92	0.47	3.87	1.00	0.05	2.51	1.00-6.27
Age	−0.37	0.23	2.64	1.00	0.10	0.69	0.44-1.08
Educational level	−0.46	0.26	2.97	1.00	0.08	0.63	0.38-1.06
Marriage			6.28	2.00	0.04		
Single	−4.03	1.67	5.84	1.00	0.02	0.02	0.00-0.47
Married	−2.60	1.41	3.43	1.00	0.06	0.07	0.00-1.16
Monthly income	−0.69	0.27	6.60	1.00	0.01	0.50	0.30-0.85
Exercise intensity	−1.16	0.38	9.45	1.00	0.00	0.31	0.15-0.66
Cancer classifications			14.40	7.00	0.04		
Digestive system malignancies	2.61	0.89	8.52	1.00	0.00	13.60	2.36-78.43
Hematological malignancies	0.96	1.06	0.81	1.00	0.37	2.60	0.32-20.98
Gynecologic malignancies	0.15	1.15	0.02	1.00	0.90	1.16	0.12-11.08
Lung cancers	0.91	0.96	0.90	1.00	0.34	2.48	0.38-16.18
Breast cancers	2.61	0.97	7.24	1.00	0.01	13.56	2.03-90.61
Head and neck malignancies	2.10	0.71	8.78	1.00	0.00	8.13	2.03-32.50
Skin cancers	0.83	0.79	1.10	1.00	0.29	2.29	0.49-10.81
Cancer treatments			17.50	2.00	0.00		
Surgery	−2.08	0.60	11.94	1.00	0.00	0.13	0.04-0.41
Chemotherapy or radiotherapy	1.71	1.38	1.54	1.00	0.22	5.55	0.37-83.19
Self-control	−0.16	0.07	4.99	1.00	0.03	0.85	0.74-0.98
Confrontation	−0.37	0.07	29.88	1.00	0.00	0.69	0.61-0.79
Avoidance	−0.19	0.06	8.63	1.00	0.00	0.83	0.73-0.94
Subjective support	−0.20	0.08	6.94	1.00	0.01	0.82	0.71-0.95

Omnibus tests of model coefficients: χ^2=555.474, *P*<0.001, Cox and Snell R^2=0.497. CI: Confidence interval, SE: Standard error, Df: Degree of freedom

following aspects. First, exercise can enhance immune function and decrease inflammatory factors. Cancer patients who participate in exercise can increase their natural killer cell activity and decrease insulin-like growth factors and cytokines, which may be involved in the etiology of their cancer. Second, increased participation in exercise interventions helps to maintain physical and psychological health, including muscle strength and psychological endurance. Third, patients who exercise regularly feel less distress and fatigue during adjuvant therapy.[42] Therefore, patients with a higher intensity of exercise may have a lower degree of distress. This result implies that exercise interventions may indirectly influence the psychological emotions of cancer patients. As the AYA population has unique diseases and psychosocial characteristics, exercise therapy for other diseases cannot be directly applied to young cancer patients.[43] Tailored exercise regimens should be developed for the AYA population.

In the present study, we found that coping and social support patterns were associated with psychological distress among AYA cancer patients, which is consistent with other studies.[17,19,29] Some studies have also revealed that AYAs present with a more limited skill set in the domains of problem solving/coping, communication, and emotional management than older adults.[17,18] Therefore, it seems that improving coping skills and social support are

potential methods to relieve distress among AYA cancer patients.

Moreover, patients with lower self-control of character strengths were found to have a higher level of distress. Similar findings were found in previous studies.[17,18] Character strengths are stress-defense factors that help young adults adapt to stress psychologically and physically. Character strengths can be promoted actively or passively.[25] In this study, we found that AYA cancer patients with self-controlled character strength had less distress. This may be related to a stronger self-awareness and empowerment among patients who were self-controlled. This suggests that we should pay attention to the important role of AYA cancer patients' character strengths when considering interventions targeted at psychological distress. Traditional psychology holds the view that character strengths are difficult to change. However, from the perspective of positive psychology in clinical areas, it may be possible to formulate interventions targeted at enhancing personality character strengths to relieve distress, especially in the self-control dimensions.[25,44]

We acknowledge the limitations of this study. First, although the participants of this study were recruited from four hospitals in Hunan Province, its epidemiological representativeness may be challenged. Second, the study was cross-sectional, and it may not properly infer the direction of causality from any significant relationship. Third, self-reporting methods are susceptible to different sources of inaccuracy.

Conclusions

The prevalence of psychological distress in AYA cancer patients was relatively high. AYAs' gender, age, educational level, marriage, monthly income, exercise intensity, cancer classifications, treatments, self-control, confrontation, avoidance, and subjective support were all associated with distress. Potential interventions targeting exercise intensity, character strengths, medical coping, and social support may decrease the prevalence of psychological distress.

Conflicts of interest

There are no conflicts of interest.

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