



Original Article

Mediating effect of ill perception on the relationship between social constraints and fear of cancer recurrence among adolescent and young adult survivors who underwent hematopoietic stem cell transplantation



Zhiying Shen^{a,b}, Jianfei Xie^b, Chunhong Ruan^{a,b,*}, Chengyuan Li^{a,b,*}

^a Department of Hematology, Third Xiangya Hospital, Central South University, Changsha, China

^b Department of Nursing, Third Xiangya Hospital, Central South University, Changsha, China

ARTICLE INFO

Keywords:

Social constraints
Ill perception
Fear of cancer recurrence
Adolescent and young adult
Hematopoietic stem cell transplantation
Survivors

ABSTRACT

Objective: We aimed to investigate the effect of ill perception (IP) on the relationship between social constraints (SC) and fear of cancer recurrence (FCR) among adolescent and young adult survivors who underwent hematopoietic stem cell transplantation (AYA-HSCT survivors).

Methods: A total of 135 AYA-HSCT survivors were interviewed using the social constraints scale, the brief illness perception questionnaire and the fear of cancer recurrence inventory (short form). Next, the mediating effect of IP on the relationship between SC and FCR was analyzed.

Results: A total of 79.3% (107/135) of the interviewed AYA-HSCT survivors revealed that they had clinical FCR. Notably, FCR had a significant positive correlation with both SC ($r = 0.362, P < 0.001$) and IP ($r = 0.457, P < 0.001$). Moreover, IP accounted for 42.1% of the total mediating effect on the relationship between SC and FCR in AYA-HSCT survivors.

Conclusions: Scientific management of FCR is one of the most common and unmet needs of AYA-HSCT survivors. Results of the present study indicate that SC has a direct effect on FCR in AYA-HSCT survivors, affirming the need for families and social networks for AYA-HSCT survivors to encourage greater expression. Also, health professionals should educate survivors and their families on the importance of cancer home care. They should also empower survivors and their families with professional information, as well as practical, interpersonal, and emotional support. Our results further show that IP partially affects the relationship between SC and FCR. Therefore, the development and implementation of targeted interventions is imperative to the improvement of survivors' IP.

Introduction

Hematopoietic stem cell transplantation (HSCT) is a common therapeutic procedure for patients with hematological malignancies and other life-threatening blood disorders. Although the development of therapeutic methods has improved the survival rate of HSCT patients, cancer recurrence remains a major cause of death among HSCT survivors.¹ Fear of cancer recurrence (FCR), which is defined as the “fear, worry, or concern relating to the possibility that cancer will come back or progress,” is considered a normal response to cancer diagnosis.² However, it has been associated with the development of dysfunctions like difficulty in sleeping, altered health behaviors, and reduced quality of life.^{3,4} At present, the risk of cancer recurrence is a significant factor affecting HSCT survivors.^{5,6} For

example, previous studies have shown that the incidence of FCR in HSCT survivors is about 50%–90%^{5,7,8} being more severe among survivors who are 55 years old and younger compared with those older than 55 years.⁸ However, none of these studies described specific details of the adolescent and young adult (AYA) age group who underwent HSCT.

In 2020 alone, there was a 1.25 million increase in the global figures of AYA diagnosed with cancer, of which blood system cancer accounted for 159,000.⁹ Notably, the 15–39 years age bracket represents a critical transition period among AYA occasioned by the focus on completing major life events or goals including completing studies, getting a job, starting a family and building a social network. Therefore, cancer diagnosis may disrupt the normal development trajectory among individuals in this age group.¹⁰ Some workers have shown that AYA cancer survivors

* Corresponding authors.

E-mail addresses: ruanchunhong_xy@163.com (C. Ruan), lichenyuan_xy3@163.com (C. Li).

<https://doi.org/10.1016/j.apjon.2022.03.012>

Received 17 January 2022; Accepted 31 March 2022

2347-5625/© 2022 The Authors. Published by Elsevier Inc. on behalf of Asian Oncology Nursing Society. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

experience higher levels of FCR than healthy people, and patients from other age groups.^{11,12} The high recurrence rate associated with HSCT despite being an effective treatment for AYA with hematological malignancies with promises for recovery and restoration to normalcy, aside this, the huge medical costs associated with HSCT ultimately predispose patients and their families to the risk of financial impoverishment and psychological maladjustment.¹³ For example, AYA cancer survivors who underwent HSCT (AYA-HSCT survivors), were reported to have higher levels of psychological burden and worse social functioning compared with those in other age groups.^{14,15} To date, however, nothing is known regarding the level of FCR in AYA-HSCT survivors.

At present, most of the theoretical models related to FCR are based on cognitive behavioral paradigms, including the self-regulation model of illness (SRMI),¹⁶ self-regulatory executive functioning model,¹⁷ social-cognitive processing model (SCPM),^{18,19} and the uncertainty in illness theory.²⁰ Among these, SRMI is the most widely used to date. The proponents of the SRMI posit that the key factor of FCR is illness perception (IP), emphasizing that individuals respond negatively to trigger factors because of their negative cognition of disease.²¹ According to this theory, an individual's cognitive and emotional processing systems are activated when they perceive somatic symptoms or health threats. Consequently, this phenomenon guides them to make coping responses, and form a feedback loop by evaluating the coping responses, and finally form a complete self-regulation system. In fact, the IP has been shown to influence the psychological adjustment and health behavior of individuals suffering from various diseases.²² For example, results from a large-scale meta-analysis demonstrated that IP has a significant impact on important outcomes like pain, health, social function, and disease status.²³ Further evidence showed that individuals who viewed cancer as a chronic disease with uncontrollable negative consequences, as well as those who were more physically and emotionally stimulated, had higher levels of FCR than those who had positive attitudes about the disease.¹⁶ This position was corroborated by researchers who followed HSCT patients for a year and found that those who felt better control over their cancer status and who had a better understanding of their disease had better mental health and active health practices.²²

Although the SRMI proposed IP as an important part of the mechanism of FCR, it failed to consider the role of social factors—one of the most fundamental attributes of human beings. It is difficult to portray the full picture of a problem or to discuss psychological reactions/emotional changes of patients without considering their social environment. The SCPM model indicates that an individuals' social network plays an important role in facilitating the cognitive processing of cancer-related memories, thoughts, and concerns.¹⁹ Particularly, cognitive processing refers to “mental activities that help people to interpret traumatic events in personally meaningful terms integrate threatening or confusing aspects of the experience into a coherent and nonthreatening conceptual framework, and reach a state of emotional acceptance.”¹⁹ According to the SCPM, social support may enhance psychological adjustment, while unsupportive reactions can constrain the expression of thoughts and feelings, thereby interfering with the cognitive processing of a traumatic event.²⁴ Social constraint (SC), on the other hand, refers to social interactions that discourage, limit, or modify a person's expression of thoughts and feelings. SC is a form of negative social response to attempts to discuss the cancer experience.¹⁸ Although SC is usually not intentional, it is present in everyday social communication and remains stable over time.²⁵ For example, there may be a social constraint when a cancer survivor tells a colleague his fear of relapse and the response is “Don't worry, you'll be fine.” The colleague tries to be emotionally supportive, but in doing so may inadvertently prevent a cancer survivor from sharing his/her concerns. According to the SCPM model, discussing stressful events such as cancer recurrence in a supportive social environment can help individuals perform good cognitive processing, thus improving the psychological adaptation process. Conversely, overt or covert restrictive behaviors in the social environment makes patients to avoid thinking or talking about stressful events, thereby forming non-adaptive coping

styles, such as avoidance, self-blame, meditation, and catastrophizing. These ultimately exacerbate psychological stress and impair psychological adjustment.¹⁸ Simonelli et al.²⁶ reviewed the theories related to FCR and proposed a conceptual model of key components. Notably, they proposed that the social environment may further influence the evaluation and processing of FCR cues such as physical symptoms, side effects, cancer-related media, and medical follow-up. Although existing studies have established a basis for exploring the effects of SC on FCR, only a handful of them have focused on breast cancer patients.^{27–29} To the best of our knowledge, no studies have demonstrated the impact and underlying mechanisms of SC on FCR in AYA-HSCT survivors.

In the present study, we hypothesized that SC, in combination with SRMI and SCPM, affects FCR through the mediating role of IP in AYA-HSCT survivors. Therefore, this cross-sectional study sought to achieve the following objectives: (1) to investigate the level of SC, IP and FCR of AYA-HSCT survivors; and (2) to explore the mechanism of IP on the relationship between SC and FCR, with a view to provide a reference for promoting the mental health of AYA-HSCT survivors.

Methods

Participants

This cross-sectional correlational study was conducted at the Third Xiangya Hospital of Central South University, in Hunan province of China using convenience sampling technique. Patients were recruited from the hospital's outpatient and HSCT database over a period of 8 months (from May to December 2021). The inclusion criteria for survivors were as follows: (1) being 15–39 years old; (2) ability to speak Mandarin and read Chinese questionnaires; (3) having undergone HSCT within 5 years as at the commencement of the survey (5-year survival rates for cancer are generally associated with a good prognosis)³⁰ and; (4) having an understanding of the purpose and process of the study and giving an informed consent. Conversely, survivors were excluded if they: (1) were diagnosed with other serious diseases, such as other cancers, acute myocardial infarction, cerebral hemorrhage or chronic renal failure; (2) were diagnosed with psychological or mental impairment according to the International Classification of Diseases (ICD) guideline, or were on psychotherapy and; (3) have experienced cancer recurrence.

Procedure

On-site investigations were conducted by two trained researchers. Each AYA-HSCT survivor in the outpatient department was provided with information on the purpose, content, investigation procedures and anonymity of respondents. Upon signing an informed consent form, each survivor filled a self-administered (self-completed) questionnaire. Thereafter, all completed questionnaires were immediately collected onsite and checked for missing information to ensure data integrity. In addition, we conducted an online survey, where we invited survivors to fill out the same questionnaire on a social networking tool (WeChat). The survivors were screened from the hospital's HSCT database, requested to participate via telephone upon which they were sent a link to a questionnaire website to fill out. Those who agreed to participate gave verbal consent. In order to improve the quality of the online survey, the questionnaire could only be answered once for each IP address, with those with a filling time of less than 5 min excluded from further analysis. This study was reviewed and approved by the Ethics Committee of the Third Xiangya Hospital (RNI 2033).

Measures

Sociodemographic and clinical characteristics

The following pieces of information about survivors' sociodemographic and clinical characteristics were collected using a self-administered questionnaire: age, gender, marital status, education,

family annual income per capita, religious belief, occupation, pretransplant cancer diagnosis, type of HSCT, and years since transplant.

Social constraints scale

The social constraints scale (SCS) is a 15-item self-reporting measure of social responses that inhibit the expression of cancer-specific thoughts, feelings, and experiences.²⁴ The items are scored on a 4-point Likert scale as follows: 1 = Never; 2 = Occasionally; 3 = Sometimes; 4 = Always. The range of possible total scores is 15–60, with a higher score implying a higher social constraint. The Chinese version of the SCS was translated by You et al.³¹, and used among Chinese breast cancer survivors. In this study, the Cronbach's α coefficient of the scale was 0.84.

Brief illness perception questionnaire

The brief illness perception questionnaire (BIPQ) is a 9-item scale that measures survivors' cognitive and emotional illness representation of any health condition based on the SRMI.³² BIPQ has been widely used in many countries, with proven excellent psychometric characteristics.³³ Specifically, the scale adopts a 10-point Likert scale, of which item 9 (not included in the total score) is an open-ended question on patients' self-attribution of disease (range: 0–80). A higher total score implies a higher negative perception of disease. The Cronbach's α coefficient of the scale in this study was 0.71.

Fear of cancer recurrence inventory short form

The fear of cancer recurrence inventory short form (FCRI-SF) is a 9-item self-reporting questionnaire that can be used to screen and measure outcomes to assess FCR.³⁴ Specifically, the questionnaire assesses the presence, frequency, intensity, and duration of thoughts associated with FCR. The tool's total scores range from 0 to 36, with higher scores indicating higher levels of FCR. A cutoff score of 13 or higher on the FCRI-SF was associated with optimal sensitivity and specificity rates for the screening of clinical levels of FCR.^{34,35} The Cronbach's α coefficient of FCRI-SF in this study was 0.74.

Data analysis

Data were analyzed using IBM SPSS Statistics (Version 24.0, Armonk, NY, USA). Continuous variables, with a normal distribution, were expressed as means \pm standard deviations (SD), while categorical variables were summarized as absolute numbers and percentages. SC, IP, and FCR scores among AYA-HSCT survivors with different socio-demographic and clinical characteristics were compared using *t*- and χ^2 -tests, whereas the correlation between quantitative variables was determined using the Pearson correlation coefficient. Mediating effects were estimated using linear regression models and interpreted as described by Baron and Kenny.³⁶ Variables that were statistically significant ($P < 0.05$) in univariate analyses were treated as control variables in mediating effect analysis. An IP variable was considered a mediator if: (1) SC had a direct effect on FCR (Path c); (2) SC significantly predicted IP (Path a); and (3) IP significantly predicted FCR when controlling for SC (Path b). Path c' indicated the direct impact of SC on FCR after controlling for IP, which was considered partial mediation in case its regression coefficient was significant. Since the sampling distribution shape was unknown among small samples, we employed a bootstrap approach to verify the existence of a mediation effect.³⁷ The significance level was set at 0.05 for a two-sided test.

Results

Sample characteristics

In this study, 82 and 68 questionnaires were distributed on-site and online, respectively, of which 80 and 55 were valid questionnaires,

totaling to 135 questionnaires. The demographic and clinical characteristics of the 135 survivors in the study are presented in Table 1. The mean age of the participants was 30.6 years (SD = 10.7 years). More than half of the patients (62.2%) were male, 40.0% had graduated from university or above, and 48.9% had a family annual income per capita of 30,000–99,999 Chinese yuan. The majority of the patients in the study population were unemployed (63.7%) and had no religious belief (78.5%). Two-thirds of the participants (75.6%) were diagnosed with acute leukemia, 90.4% received allogeneic-HSCT, and 40.7% underwent HSCT within one year.

Scores of SC, IP, and FCR in AYA-HSCT survivors

The average scores for SC, IP, and FCR were 29.39 ± 7.61 , 42.84 ± 7.20 , and 16.20 ± 4.16 , respectively (Table 1). A total of 107 survivors (79.3%) experienced clinical FCR levels. Regarding demographic variables, women had higher scores than men in SC, IP, and FCR ($P < 0.01$). Respondents educated up to junior middle school or below had significantly higher levels of SC and FCR than respondents with higher education ($P < 0.01$). The IP of survivors with family annual income per capita $\geq 100,000$ Chinese yuan was lower than that of survivors with family annual income per capita of $< 30,000$ and $30,000$ – $99,999$ ($P < 0.01$).

The relationship between SC, IP, and FCR

FCR scores were significantly correlated with both SC ($r = 0.362$, $P < 0.01$) and IP ($r = 0.457$, $P < 0.01$). Similarly, the SC score was also positively correlated with IP ($r = 0.410$, $P < 0.01$).

IP plays a mediating role between SC and FCR

After controlling for socio-demographic and clinical variables (gender, education, and family annual income per capita), it was evident that SC had a significant total effect on both FCR (Path c: $B = 0.198$, $P < 0.001$) and IP (Path a: $B = 0.388$, $P < 0.001$). Furthermore, IP had a positive impact on FCR (Path b: $B = 0.215$, $P < 0.001$), while SC directly affected FCR after controlling for IP (Path c': $B = 0.115$, $P < 0.001$). Next, we determined the mediating effect of IP in 5000 bootstrap samples based on a 95 CI%, and found a significant effect of IP as a mediating factor (95 CI%: 0.067–0.251, $Z = 20.616$, $P < 0.01$). The regression correlation coefficients of path c' was significant, indicating that IP had a partial mediating effect on the relationship between SC and FCR. Moreover, SC partially predicted FCR of AYA-HSCT survivors through IP, while the mediating effect accounted for 42.1% ($0.388 \times 0.215/0.198$) of the total effect. The mediating effects of IP on SC and FCR are outlined in Table 2. The mediating effect model is shown in Fig. 1.

Discussion

Results from a previous systematic review reported that 31%–85.2% of AYA cancer survivors experienced some level of FCR, of which 13%–62% were high level, underpinning its relevance as an important unmet need.³⁸ In the present study, 79.3% of AYA-HSCT survivors reported clinical FCR. In another cross-sectional study, Brice et al.³⁹ analyzed 364 HSCT survivors and found that about 11% of the respondents lived with severe FCR, while only 5% exhibited no FCR. The contrasting findings between our study and their study may be attributed to the different FCR assessment tools employed, as well as differences in HSCT survivors recruited. High medical expenses associated with HSCT pose a heavy financial burden on families and societies in China and the rest of the world. Specifically, the upfront cost of manpower and money makes patients more fearful of a recurrence, which could mean another transplant or even death. At the same time, AYA cancer patients are more afraid of recurrence owing to the fact that they bear academic, family, and social responsibilities, and hope to create value for their families and

Table 1
Scores on SC, IP and FCR of AYA-HSCT survivors of different characteristics (n = 135).

Variables	n (%)	SC	IP	FCR
Gender				
Male	84 (62.2)	27.70 ± 7.63	41.55 ± 5.53	15.26 ± 3.00
Female	51 (37.8)	32.16 ± 6.77	44.98 ± 8.98	17.75 ± 5.25
t-value		3.428	2.462	3.084
P-value		0.001 ^a	0.016*	0.003 ^a
Marital status				
Married	67 (49.6)	29.27 ± 7.93	42.36 ± 7.64	15.66 ± 3.97
Single	68 (50.4)	29.50 ± 7.33	43.32 ± 6.76	16.74 ± 4.31
t-value		0.176	0.778	1.512
P-value		0.861	0.438	0.133
Education				
Junior middle school or lower	30 (22.2)	35.73 ± 6.05	44.60 ± 7.29	18.37 ± 5.16
Senior high school or secondary specialized school	51 (37.8)	28.61 ± 6.23	43.43 ± 6.89	16.55 ± 3.87
University or higher	54 (40.0)	26.59 ± 7.64	41.31 ± 7.25	14.67 ± 3.15
F-value		17.985	2.327	8.823
P-value		0.000 ^a	0.102	0.000 ^a
Family annual income per capita (RMB)				
< 30,000	60 (44.4)	28.93 ± 7.35	42.25 ± 6.34	16.15 ± 3.99
30,000–99,999	66 (48.9)	30.08 ± 7.34	44.33 ± 7.66	16.42 ± 4.41
≥ 100,000	9 (6.7)	27.33 ± 11.07	35.89 ± 4.46	14.89 ± 3.59
F-value		0.702	6.278	0.542
P-value		0.497	0.002 ^a	0.583
Religious belief				
Yes	29 (21.5)	31.41 ± 6.10	42.79 ± 7.72	15.66 ± 4.02
No	106 (78.5)	28.83 ± 7.91	42.86 ± 7.09	16.35 ± 4.21
t-value		1.630	0.043	0.794
P-value		0.105	0.966	0.429
Occupational status				
Full/part time	49 (36.3)	28.20 ± 7.30	44.39 ± 7.09	17.04 ± 3.88
No	86 (63.7)	30.06 ± 7.74	41.97 ± 7.15	15.72 ± 4.26
t-value		1.366	1.899	1.785
P-value		0.174	0.060	0.076
Pretransplant cancer diagnosis				
Acute leukaemia	102 (75.6)	29.87 ± 7.47	43.03 ± 7.38	16.54 ± 4.44
Other	33 (24.4)	27.88 ± 7.95	42.27 ± 6.67	15.15 ± 2.99
t-value		1.722	0.274	2.806
P-value		0.192	0.601	0.096
Type of HSCT				
Autologous	13 (9.6)	30.20 ± 5.35	43.50 ± 6.95	16.19 ± 4.19
Allogeneic	122 (90.4)	29.33 ± 7.65	42.76 ± 7.20	17.01 ± 3.33
t-value		0.399	0.353	0.823
P-value		0.690	0.724	0.412
Years since transplant				
≤ 1 year	55 (40.7)	29.16 ± 6.80	42.02 ± 6.60	15.67 ± 4.81
1–3 year	46 (34.1)	29.26 ± 7.95	42.15 ± 7.11	16.80 ± 3.22
3–5 year	34 (25.2)	29.91 ± 8.53	45.12 ± 7.94	16.24 ± 4.18
F-value		0.109	2.316	0.926
P-value		0.896	0.103	0.399

^a P < 0.01, *P < 0.05; SC, social constraint; IP, illness perception; FCR, fear of cancer recurrence; AYA, adolescent and young adult; HSCT, Hematopoietic stem cell transplantation

society rather than become a burden.³⁸ Results of the present study identified gender and educational level as potential risk factors for FCR, consistent with previous studies that found similar influencing factors of FCR among HSCT survivors.^{5,11,40} Worrying about cancer recurrence is normal, and maintaining a reasonable FCR allows patients to be more compliant with their doctors' treatment instructions, and allows possible early detection of potential recurrence.¹⁶ However, previous studies have shown that high FCR levels, mainly clinically significant FCR, can elicit a

Table 2
Summary of the mediating effects of IP on the relationship between SC and FCR (n = 135).

Effect	Path	B	SE	T	P-value
Total effect	SC→FCR	0.198	0.044	4.475	< 0.01
Indirect effect	SC→IP	0.388	0.075	5.183	< 0.01
Indirect effect	IP→FCR	0.215	0.048	4.476	< 0.01
Direct effect	SC→FCR	0.115	0.045	2.529	< 0.01

SC, social constraint; IP, illness perception; FCR, fear of cancer recurrence; B, unstandardized coefficient; SE, standard error

heightened state of alertness or fear to physical sensations or symptoms, as well as constant worry, fear, and anxiety associated with cancer recurrence.⁴¹ Consequently, attention should be paid to the unmet needs of AYA-HSCT survivors, in order to avoid or at least minimize the negative impact of high intensity fear of recurrence among survivors.

Results of the present study also revealed an SC score of 29.39 ± 7.61 in young HSCT patients, with a mean score of 1.96 ± 0.51, which was lower than the findings of Nenova et al.⁴² among 49 HSCT patients. The difference between the results can be attributed to the age difference of respondents and assessment tools (unlike our study, they recruited adults over 18 years old and adopted a 10-item SCS scale as an assessment tool). Furthermore, we found a significant positive correlation between SC and FCR in AYA-HSCT survivors while results of hierarchical regression analysis also showed that SC was an independent predictor of FCR after controlling for socio-demographic and clinical information. These results were consistent with the findings of several previous studies among breast cancer patients.^{27,28,43}

Numerous researchers have demonstrated the effects of HSCT on patients' interpersonal relationships and social networks.^{44,45} Firstly,

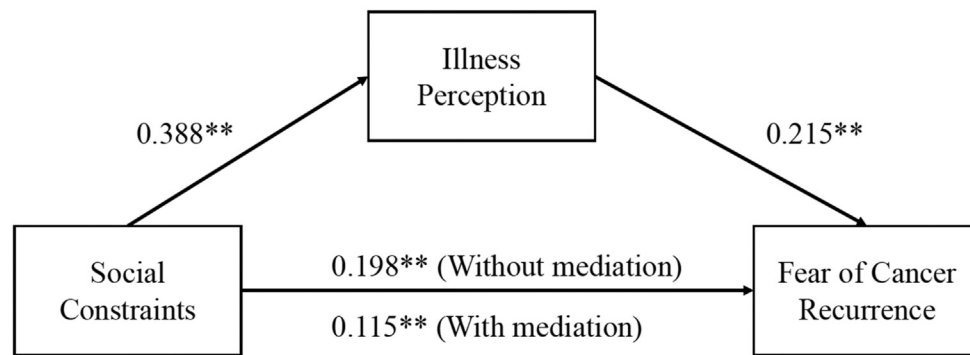


Fig. 1. Mediating role of illness perception on the relationship between social constraints and fear of cancer recurrence.

their social circle shrinks, and some survivors face various challenges like discrimination, career derailment, job insecurity, and mental limitations as a result of their illness. These challenges make them to withdraw from social circles. Secondly, they are shunned by family and friends, when discussing cancer or transplants. Previous studies have shown that although patients feel that experiencing HSCT makes family life more connected and positive, they also fear being perceived as “weak” or “pathetic” by family and friends.⁴⁶ Consequently, they are reluctant to talk to medical staff or family members because they can neither understand what they are going through nor their deep psychological experiences. Therefore, their psychological experiences constitute a phenomenon that disrupts their communication with partners and other family members. In general, social support is associated with less pain and more happiness, while SC is often associated with distress such as anxiety, depression, fear, post-traumatic stress disorder, and worry.^{47,48} In order to reduce SC perceived by survivors, health personnel, and volunteers should encourage and help survivors to return to work, while guiding their families and friends to provide positive emotional support.

Again, results of the present study revealed that the total score based on the BIPQ scale was 42.84 ± 7.20 , which was slightly higher than that reported by Valenta et al.⁴⁹ who used the same assessment tool but without age stratification. In addition, our results showed that male AYA-HSCT survivors and those with a high family income exhibited lower IP levels, indicating that they had lower negative perception of the disease. We hypothesized that high-income patients could cope with the costs of repeated follow-up and medication after transplantation, and enjoy greater access to medical resources and have a greater sense of control over their disease. Results from several studies have demonstrated that apperception of a greater sense of control and fewer consequences of one's illness are linked to better social, emotional, functional health, less distress, anxiety, and depression among HSCT recipients.^{49,50} Therefore, patients with lower income levels should be concerned about whether they have excessive negative disease perception. In addition, results indicated that IP was not only positively correlated with FCR but was also an independent predictor of FCR for AYA-HSCT survivors, consistent with the findings of previous studies that focused on patients with breast cancer, bladder cancer, or lung cancer.^{51–53} This result was also consistent with the view of SRMI proponents that patients with negative disease perception will exhibit higher FCR levels. Based on this, disease perception should be considered a starting point for prevention of FCR, affirming the need to reduce patients' FCR from the perspective of cognitive intervention.

In the present study, IP (with a value of 42.1%) exerted a significant mediating effect on the relationship between SC and FCR. This is consistent with the findings of a previous study which confirmed the mediating effect of IP on the association between SC and FCR among patients with breast cancer.⁵⁴ Similarly, Mikrut et al.⁵⁵ conducted a survey of 66 primary caregivers caring for young cancer patients and found that greater SC was associated with worse cognitive processing and

higher FCR, and ultimately with more severe depressive symptoms. These results also support the theoretical framework of this study, which suggested that SC is an extrinsic influence factor that hinders positive cognitive processing of cancer-related problems and leads to negative disease perception. Over time, this perception causes persistent mental health intrusion and heightened arousal, which in turn leads to unreasonable FCR levels. In the traditional Chinese mindset, cancer often signifies disaster and bad luck, and limiting responses from others may remind survivors that they have cancer or even they are a burden to their families. This reinforces survivors' self-humiliation and leads to prolonged emotional distress and negative perception of disease. Furthermore, this stress and negative perception can worsen FCR because survivors know that a relapse means an unbelievable increase in the burden to their family and more difficulties in returning to social life.

Based on our findings, we put forward some recommendations for the clinical management of FCR for AYA-HSCT survivors. Firstly, there is a need to create a positive social environment around AYA-HSCT survivors in order to encourage them to freely express their emotions and communicate their ideas, as this will help reduce the level of FCR. In addition, assessment of survivors' family and social environment should not be ignored. Secondly, AYA-HSCT survivors with high SC should be granted facilitated access to health care professionals with good knowledge of cancer follow-up care, because they constitute an important source of social support. Knowledgeable healthcare professionals have been shown to contribute to the mental health of survivors by providing information, utility, interpersonal and emotional support.^{56,57} Thirdly, IP had a partial mediating effect on the relationship between SC and FCR. Some previous studies have shown that cognitive behavioral therapy (CBT) intervention,^{58,59} mindfulness-based cognitive therapy,⁶⁰ and internet-based psychotherapeutic intervention⁶¹ can significantly reduce AYA cancer patients' FCR by adjusting disease perception. Therefore, targeted interventions for improving survivors' negative IP should be developed and deployed.

Limitations

This study had some limitations. Firstly, we only selected AYA survivors who received HSCT in a hospital in Changsha, Hunan Province, China, which represented only a small sample size. Secondly, this study adopted an across-sectional design, and lacked follow-up of survivors across different time periods. Further studies, using a multi-center, and large-sample longitudinal cohort is needed to validate the observed trajectory of FCR, examine its dynamic changes, and provide a reference for clinical development of targeted intervention.

Conclusions and recommendations

Results of the present study demonstrated that SC directly affects FCR for AYA-HSCT survivors. Our results further indicated that IP has a

partial significant mediating effect on the relationship between SC and FCR. We therefore recommend as follows:

1. AYA-HSCT survivors should be provided with family and social network support, to encourage their expression. Also, health professionals should educate survivors and their families on cancer home care and provide them with professional information, practical, interpersonal, and emotional support.
2. Targeted interventions should be developed and deployed to improve survivors' negative illness perception. Moreover, some behavioral cognitive therapy that improves survivors' perception of the disease may be useful.

Author contributions

Conceived and designed the analysis: Zhiying Shen, Chunhong Ruan, Chengyuan Li, Collected the data: Zhiying Shen, Chunhong Ruan, Chengyuan Li, Contributed data or analysis tools: Zhiying Shen, Jianfei Xie, Performed the analysis: Zhiying Shen, Jianfei Xie, Wrote the paper: Zhiying Shen.

Funding

Nil.

Declaration of competing interest

None declared.

Acknowledgments

The authors would like to thank TopEdit (www.topeditsci.com) for its linguistic assistance during the preparation of this manuscript. This study was approved by the Ethics Committee of the Third Xiangya Hospital (Approval No. RNI 2033).

References

1. D'Souza A, Fretham C, Lee SJ, et al. Current use of and trends in hematopoietic cell transplantation in the United States. *Biol Blood Marrow Transplant.* 2020;26:e177–e182.
2. Lebel S, Ozakinci G, Humphris G, et al. From normal response to clinical problem: definition and clinical features of fear of cancer recurrence. *Support Care Cancer.* 2016;24:3265–3268.
3. Mehnert A, Koch U, Sundermann C, Dinkel A. Predictors of fear of recurrence in patients one year after cancer rehabilitation: a prospective study. *Acta Oncol.* 2013; 52:1102–1109.
4. Séguin Leclair C, Lebel S, Westmaas JL. The relationship between fear of cancer recurrence and health behaviors: a nationwide longitudinal study of cancer survivors. *Health Psychol.* 2019;38:596–605.
5. Sarkar S, Scherwath A, Schirmer L, et al. Fear of recurrence and its impact on quality of life in patients with hematological cancers in the course of allogeneic hematopoietic SCT. *Bone Marrow Transplant.* 2014;49:1217–1222.
6. Syrjala KL, Martin PJ, Lee SJ. Delivering care to long-term adult survivors of hematopoietic cell transplantation. *J Clin Oncol.* 2012;30:3746–3751.
7. Mcquellon RP, Duckworth KE, Campbell CR, Russell GB, Hurd DD. Fear of cancer recurrence, distress, depressive symptoms, and quality of life in hematopoietic stem cell transplantation patients. *J Psychosoc Oncol.* 2019;1:e12.
8. Hefner J, Kapp M, Drebing K, et al. High prevalence of distress in patients after allogeneic hematopoietic SCT: fear of progression is associated with a younger age. *Bone Marrow Transplant.* 2014;49:581–584.
9. International Agency for Research on Cancer. Estimated number of new cases in 2020, Hodgkin lymphoma, leukaemia, non-hodgkin lymphoma, multiple myeloma, both sexes, ages 15-39. Available from: <https://geo.iarc.fr/today/home>. [Last accessed on 2021 Dec 02].
10. Society for Adolescent Health and Medicine. Young adult health and well-being: a position statement of the society for adolescent health and medicine. *J Adolesc Health.* 2017;60:758–759.
11. Shay LA, Carpentier MY, Vernon SW. Prevalence and correlates of fear of recurrence among adolescent and young adult versus older adult post-treatment cancer survivors. *Support Care Cancer.* 2016;24:4689–4696.
12. Ziner KW, Sledge GW, Bell CJ, Johns S, Miller KD, Champion VL. Predicting fear of breast cancer recurrence and self-efficacy in survivors by age at diagnosis. *Oncol Nurs Forum.* 2012;39:287–295.
13. Tewari P, Franklin AR, Tarek N, Askins MA, Mofield S, Kebraie P. Hematopoietic stem cell transplantation in adolescents and young adults. *Acta Haematol.* 2014;132: 313–325.
14. Tremolada M, Bonichini S, Taverna L, Basso G, Pillon M. Health-related quality of life in AYA cancer survivors who underwent HSCT compared with healthy peers. *Eur J Cancer Care.* 2018;27, e12878.
15. Walsh CA, Yi JC, Rosenberg AR, Crouch MV, Leisenring WM, Syrjala KL. Factors associated with social functioning among long-term cancer survivors treated with hematopoietic stem cell transplantation as adolescents or young adults. *Psycho Oncol.* 2020;29:1579–1586.
16. Lee-Jones C, Humphris G, Dixon R, Hatcher MB. Fear of cancer recurrence—a literature review and proposed cognitive formulation to explain exacerbation of recurrence fears. *Psycho Oncol.* 1997;6:95–105.
17. Wells A, Matthews G. Modelling cognition in emotional disorder: the S-REF model. *Behav Res Ther.* 1996;34:881–888.
18. Lepore SJ, Revenson TA. Social constraints on disclosure and adjustment to cancer. *Social and Personality Psychology Compass.* 2007;1:313–333.
19. Lepore SJ. A social-cognitive processing model of emotional adjustment to cancer. In: Baum A, Andersen BL, eds. *Psychosocial Interventions for Cancer.* 2001:99–116.
20. Mishel MH. Reconceptualization of the uncertainty in illness theory. *Image J Nurs Scholarsh.* 1990;22:256–262.
21. Fardell JE, Thewes B, Turner J, et al. Fear of cancer recurrence: a theoretical review and novel cognitive processing formulation. *J Cancer Surviv.* 2016;10: 663–673.
22. Nelson AM, Juckett MB, Coe CL, Costanzo ES. Illness perceptions predict health practices and mental health following hematopoietic stem cell transplantation. *Psycho Oncol.* 2019;28:1252–1260.
23. Hagger MS, Koch S, Chatzisarantis NLD, Orbell S. The common sense model of self-regulation: meta-analysis and test of a process model. *Psychol Bull.* 2017;143: 1117–1154.
24. Lepore SJ, Silver RC, Wortman CB, Wayment HA. Social constraints, intrusive thoughts, and depressive symptoms among bereaved mothers. *J Pers Soc Psychol.* 1996;70:271–282.
25. Badr H, Pasipanodya EC, Laurenceau JP. An electronic diary study of the effects of patient avoidance and partner social constraints on patient momentary affect in metastatic breast cancer. *Ann Behav Med.* 2013;45:192–202.
26. Simonelli LE, Siegel SD, Duffy NM. Fear of cancer recurrence: a theoretical review and its relevance for clinical presentation and management. *Psycho Oncol.* 2017;26: 1444–1454.
27. Soriano EC, Pasipanodya EC, LoSavio ST, et al. Social constraints and fear of recurrence in couples coping with early stage breast cancer. *Health Psychol.* 2018;37: 874–884.
28. Soriano EC, Otto AK, LoSavio ST, Permdorfer C, Siegel SD, Laurenceau JP. Fear of cancer recurrence and inhibited disclosure: testing the social-cognitive processing model in couples coping with breast cancer. *Ann Behav Med.* 2021;55: 192–202.
29. Yeung NCY, Lu Q. Social constraints and fear of recurrence among Chinese American breast cancer survivors: an exploration of psychosocial mediators. *Psycho Oncol.* 2022;31:98–106.
30. National cancer institute. Online Summary of Trends in US Cancer Control Measures: Survival. Available from: <https://progressreport.cancer.gov/after/survival>. [Last accessed on 2022 Mar 22].
31. You J, Lu Q. Social constraints and quality of life among Chinese-speaking breast cancer survivors: a mediation model. *Qual Life Res.* 2014;23(9):2577–2584.
32. Broadbent E, Petrie KJ, Main J, Weinman J. The brief illness perception questionnaire. *J Psychosom Res.* 2006;60:631–637.
33. Broadbent E, Wilkes C, Koschwanez H, Weinman J, Norton S, Petrie KJ. A systematic review and meta-analysis of the brief illness perception questionnaire. *Psychol Health.* 2015;30:1361–1385.
34. Simard S, Savard J. Screening and comorbidity of clinical levels of fear of cancer recurrence. *J Cancer Surviv.* 2015;9:481–491.
35. Ng DWL, Kwong A, Suen D, et al. Fear of cancer recurrence among Chinese cancer survivors: prevalence and associations with metacognition and neuroticism. *Psycho Oncol.* 2019;28:1243–1251.
36. Baron RM, Kenny DA. The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical consideration. *J Pers Soc Psychol.* 1986;51:1173–1182.
37. Preacher KJ, Hayes AF. SPSS and SAS procedures for estimating indirect effects in simple mediation models. *Behav Res Methods Instrum Comput.* 2004;36: 717–731.
38. Yang Y, Li W, Wen Y, et al. Fear of cancer recurrence in adolescent and young adult cancer survivors: a systematic review of the literature. *Psycho Oncol.* 2019;28: 675–686.
39. Brice L, McErlean G, Donovan C, et al. Fear of cancer recurrence following allogeneic haematopoietic stem cell transplantation (HSCT) for haematological malignancy: a cross-sectional study. *Eur J Oncol Nurs.* 2020;49:101845.
40. Wang R, Syed IA, Nathan PC, Barr RD, Rosenberg-Yunger ZR, Klassen AF. Exploring cancer worry in adolescent and young adult survivors of childhood cancers. *J Adolesc Young Adult Oncol.* 2015;4:192–199.
41. Mutsaers B, Butow P, Dinkel A, et al. Identifying the key characteristics of clinical fear of cancer recurrence: an international Delphi study. *Psycho Oncol.* 2020;29: 430–436.
42. Nenova M, DuHamel K, Zemon V, Rini C, Redd WH. Posttraumatic growth, social support, and social constraint in hematopoietic stem cell transplant survivors. *Psycho Oncol.* 2013;22:195–202.

43. Cohee AA, Adams RN, Johns SA, et al. Long-term fear of recurrence in young breast cancer survivors and partners. *Psycho Oncol.* 2017;26:22–28.
44. Sharin UBM, Hwang CCJ, Ang WHD, Lopez V. The haematopoietic stem cell transplant survivors' sense of coherence about their experiences: a qualitative study. *Support Care Cancer.* 2020;28:4275–4283.
45. Parisek M, Loss J, Holler E, et al. "This graft-vs.-host disease determines my life. That's it."-A qualitative analysis of the experiences and needs of allogeneic hematopoietic stem cells transplantation survivors in Germany. *Front Public Health.* 2021;9:687675.
46. Poloméni A, Lapusan S, Bompont C, Rubio MT, Mohty M. The impact of allogeneic-hematopoietic stem cell transplantation on patients' and close relatives' quality of life and relationships. *Eur J Oncol Nurs.* 2016;21:248–256.
47. Rivera Rivera JN, Burris JL. A systematic literature review and head-to-head comparison of social support and social constraint in relation to the psychological functioning of cancer survivors. *Ann Behav Med.* 2020;54:176–192.
48. Tremolada M, Bonichini S, Basso G, Pillon M. Perceived social support and health-related quality of life in AYA cancer survivors and controls. *Psycho Oncol.* 2016;25:1408–1417.
49. Valenta S, De Geest S, Fierz K, et al. Perception of late effects among long-term survivors after haematopoietic stem cell transplantation: descriptive analysis and validation of the Brief Illness Perception Questionnaire. A sub-study of the PROVIVO study. *Eur J Oncol Nurs.* 2017;27:17–27.
50. Baliouis M, Rennoldson M, Dawson DL, Mills J, das Nair R. Perceptions of hematopoietic stem cell transplantation and coping predict emotional distress during the acute phase After transplantation. *Oncol Nurs Forum.* 2017;44:96–107.
51. Qiansha W, Qingfeng W, Qingling Z, Xiao Y, Difen L, Xiaoqing L. Study on influencing factors of Fear of Cancer Recurrence in lung cancer patients Chin. *Nurs Manag.* 2020;20:1596–1600.
52. Xiaoping W, Fang H, Fan Z, Ming D, Yuanxi H. The level and factors associated with fear of progression in patients after bladder cancer surgery. *J Nurs Sci.* 2019;34:52–55.
53. Shim EJ, Lee JW, Min YH. Does depression decrease the moderating effect of self-efficacy in the relationship between illness perception and fear of progression in breast cancer? *Psycho Oncol.* 2018;27:539–547.
54. Hui R. *Influencing Factors and Developmental Trajectories of the Fear of Cancer Recurrence Among Breast Cancer Patients.* Changchun, Jilin university; 2021.
55. Mikrut EE, Panjwani AA, Cipollina R, Revenson TA. Emotional adjustment among parents of adolescents and young adults with cancer: the influence of social constraints on cognitive processing and fear of recurrence. *J Behav Med.* 2020;43:237–245.
56. Zebrack B, Chesler MA, Kaplan S. To foster healing among adolescents and young adults with cancer: what helps? What hurts? *Support Care Cancer.* 2010;18:131–135.
57. Leppla L, Mielke J, Kunze M, et al. Clinicians and patients perspectives on follow-up care and eHealth support after allogeneic hematopoietic stem cell transplantation: a mixed-methods contextual analysis as part of the SMILE study. *Eur J Oncol Nurs.* 2020;45:101723.
58. Hagström J, Ander M, Cernvall M, et al. Heeding the psychological concerns of young cancer survivors: a single-arm feasibility trial of CBT and a cognitive behavioral conceptualization of distress. *PeerJ.* 2020;8, e8714.
59. Sansom-Daly UM, Wakefield CE, McGill BC, Patterson P. Ethical and clinical challenges delivering group-based cognitive-behavioural therapy to adolescents and young adults with cancer using videoconferencing technology. *Aust Psychol.* 2015;50:271–278.
60. Nissim RS, Roth A, Gupta AA, Elliott M. Mindfulness-based cognitive therapy intervention for young adults with cancer: a pilot mixed-method study. *J Adolesc Young Adult Oncol.* 2020;9:256–261.
61. Seitz DC, Knaevelsrud C, Duran G, Waadt S, Goldbeck L. Internet-based psychotherapy in young adult survivors of pediatric cancer: feasibility and participants' satisfaction. *Cyberpsychol Behav Soc Netw.* 2014;17:624–629.