



Pictorial Representation of Illness and Self Measure-Revised 2 (PRISM-R2): an effective tool to assess perceived burden of thyroid cancer in mainland China

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Abstract

Purpose Thyroid cancer, especially differentiated thyroid cancer (DTC), is a highly prevalent chronic disease that is known to cause considerable distress, related both to the high recurrence and treatment of the disease. The Pictorial Representation of Illness and Self Measure-Revised 2 (PRISM-R2) has been developed as a visual measure to assess suffering. The aim of this study was to evaluate the ability of the instrument to identify patients with DTC with different levels of suffering who may need additional support care.

Methods Participants were 338 adult inpatients with DTC who were accepting the radioiodine for remnant ablation in the nuclear medicine department. The assessment tools included the following: (1) the PRISM-R2, yielding Self-Illness Separation (SIS) and Illness Perception Measure (IPM); (2) distress thermometer (DT), a measure of thyroid cancer-related distress; (3) posttraumatic growth inventory (PTGI); (4) 12-item Short-Form health survey (SF-12); and (5) the Supportive Care Needs Survey Short Form (SCNS-SF34). In addition, the content validity of PRISM-R2 was tested using the patients' comments.

Results SIS and IPM showed medium intercorrelation ($r = -.482$; $p < 0.01$), and both of them showed strongly significant associations with DT. SIS also showed significant correlations with one factor of PTGI (personal strength), four factors of SF-12 (general health, role-emotional, mental health, and vitality), and one factor of SCNS-SF34 (psychological needs). IPM showed significant correlations with five factors of SF-12 and all the factors of SCNS-SF34. No correlation was found between IPM and PTGI.

Conclusions PRISM-R2 is a well-accepted and understandable tool to assess the psychological burden of patients with thyroid cancer in Chinese settings. It may be useful to guide or evaluate the interventions for the patients.

Keywords PRISM-R2 · Thyroid cancer · Suffering · Quality of life · Supportive care need

Introduction

Thyroid cancer is the most common malignancy of the endocrine system, of which about 95% is differentiated thyroid cancer (DTC) [1]. Most DTCs are treated with a total thyroidectomy followed by selective use of radioiodine for remnant ablation (RRA). Survival rates are excellent, but poor quality

of life (QoL) outcomes have been reported in this group [2, 3]. Some researchers confirm that QoL in thyroid cancer is similar to that of other cancers with worse survival [4]. One study has shown that some people surviving DTC report fear of recurrences and/or long-term complications, restrictions in daily (social) life, working life, and sexual functioning resulting in deteriorated levels of QoL [5]. One factor that

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has negative effects on QoL is the level of distress [6]. Previous data suggest that patients with DTC perceive their illness as severe on a subjective, emotional basis unrelated to disease severity [7]. Living with DTC requires considerable psychological adjustment. Failure to adjust adequately to the disease may have negative consequences for the patient's QoL, possibly resulting in suffering. According to Cassell [8], suffering is defined as “a state of severe distress associated with events that threatens the intactness of the person.” From this definition, it follows that the extent of suffering is not merely determined by the severity of the illness itself, but rather by the perceived threats it poses to the intactness of the self, i.e., the impact and meaning a disease has for a patient [9]. In some sense, suffering can be seen as a qualitatively different and more severe state of physical, emotional, or social distress [10]. Based on these conceptualizations, the authors suggest that (especially in the long run) the (re)interpretations, explanations, and understanding of what has happened are essential for patients to come to terms with their disease and to place it/accept it in their lives. To assess the suffering caused by the disease and the patients' perception of impact related to the disease are the key steps to provide optimal biopsychosocial patient management. As a tool of assessing the subjective position of one's illness in relation to the self, the Pictorial Representation of Illness and Self Measure (PRISM) seems to match this clinical need rather well.

Büchi et al. [11] were the first to introduce a generic assessment method of the PRISM. It was developed as a visualization tool to measure the burden of suffering and has proved to be valid and reliable in various conditions such as chronic illness, pain, and advanced cancer [12–14]. The Pictorial Representation of Illness and Self Measure-Revised 2 (PRISM-R2) is a modified version of the original PRISM which can be used to assess the extent to which people suffer from an illness [15]. As of now, the PRISM and PRISM-R2 have been exclusively administered and evaluated in patients with current diseases or symptoms. It has been used in a wide variety of Western culture, but there is no report about their use in Eastern culture.

Thyroid cancer, especially DTC, is the most common endocrine malignancy in mainland China. Its incidence is rapidly rising [16]. Patients with DTC report impaired QoL in relation with initial surgery and hypothyroidism preceding treatment with RRA. Moreover, several studies have shown that even patients being in remission of DTC for many years reported impaired QoL compared to healthy controls [17]. In this study, patients who were receiving the RRA were chosen as the subjects. The aims of this study were the following: (a) to assess whether a modification of the original PRISM task, the PRISM-R2 is a feasible and valid instrument for measuring suffering in the population with DTC in mainland China; (b) to evaluate the properties of the PRISM-R2 by examining

its associations with the distress, posttraumatic growth, and QoL as well as its relationship with the support care needs of patients. The authors expect the PRISM-R2 to be an efficient, quick, and easy-to-use tool for both health-care providers and patients.

Methods

Participants

Participants were recruited from the Department of Nuclear Medicine of Tenth People's Hospital of Tongji University. The inclusion criteria included the following: (a) confirmed DTC and awaiting the radioiodine therapy, (b) age older than 18 years, and (c) capability to complete a battery of self-report measures. We excluded patients who had linguistic or intellectual difficulties. Between October 2014 and March 2016, 338 patients participated in the present study and completed all the questionnaires.

The study protocol was approved by the Ethical Committee of the Tongji University. All subjects signed an informed consent form prior to filling out the questionnaire. According to the treatment procedure, the patients were required to complete the therapy of RRA in hospital for 1 week. The investigation was completed before the participants drank the radioiodine.

Measures

PRISM-R2

The original PRISM [11] examines the degree of suffering by using a visual task performance. It consists of a disk (labeled as “self”) placed in the lower right corner of a white A4-sheet labeled as one's living environment. Patients are requested to place a so-called illness disk (labeled “my medical problem”) in relation to their self-disk and living environment. The PRISM-R2 [15] consists of a large circle of 186 mm in diameter, representing the respondents' life, with a 52-mm disk in diameter placed in the middle and in front of the disk, representing the respondents' self (Fig. 1). Three differently sized disks were shown on the right side of the circle, representing the respondents' illness. The illness disks were respectively smaller than, equal to, and larger than the self-disk (35, 52, and 65 mm in diameter). “My illness” is printed on each illness disk. After choosing an illness disk, patients attach it to the paper in a place relative to the self-disk that represents their view of the illness's effect on their life.

Two outcome variables are obtained with this instrument: (1) Self-Illness Separation (SIS), the distance from the center of the self to the center of the illness-disk represents which ranged from 0 to 93 mm. Following Pincus and Morley [18], a

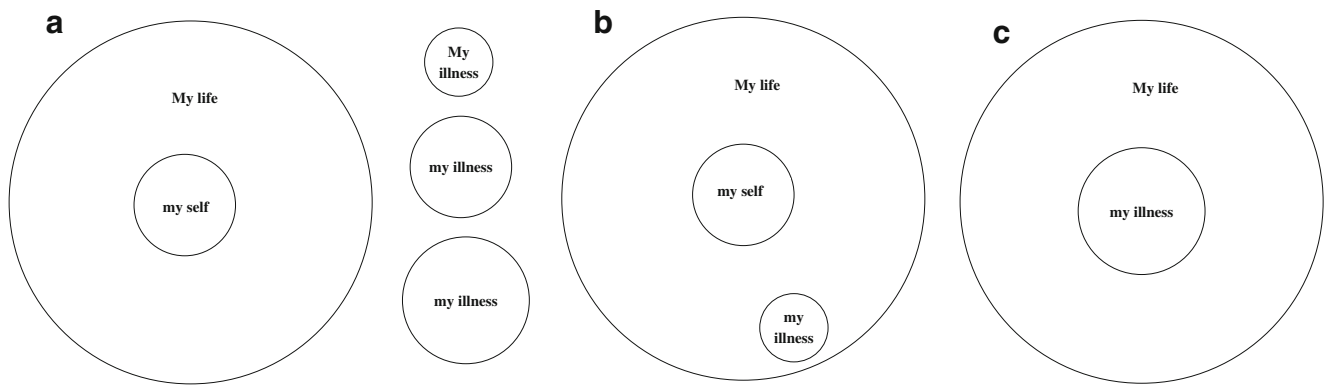


Figure 1 **a** Illustration of the PRISM-R2. **b** Illustration of PRISM with adequate coping and integration (small illness disk far away from self). **c** Illustration of PRISM with large continued impact of cancer (large illness disk close to self)

separation between illness and self schema is assumed to signify a healthy adjustment to the illness; (2) Illness Perception Measure (IPM), which represents the perceived severity of the disease, ranging from 1 to 3 (1 corresponding with the smallest illness disk and 3 corresponding with the largest), with a larger illness disk indicating a greater perceived severity of illness.

Considering cultural differences between east and west, a process of back-and-forth translation about the written instruction of the PRISM-R2 was conducted by a bilingual and bi-cultural team of professionals in order to achieve semantic and content consistent with the English version. Before the formal investigation, a pilot study was conducted in 20 patients with DTC who were going to receive the therapy of RRA to test if the respondents understood the questionnaire.

In this study, a paper version of the PRISM-R2 was used and the illness disks were provided as stickers to allow completion of all measures in hospital. Figure 1a–c illustrates the design and possible applications of the PRISM-R2.

Distress thermometer (DT)

DT is widely used as a screening measure of global psychological distress [19] and is used to assess the current level of psychological distress experienced by DTC patients. Participants were asked how distressed they felt on a single 11-point scale, ranging from 0 (no distress) to 10 (extreme distress). It has been used in patients with cancer in mainland China and demonstrated good reliability and validity [20]. The DT served to evaluate content validity of the PRISM-R2.

12-Item Short-Form health survey (SF-12)

SF-12 is a 12-item self-report questionnaire covering eight subscales: general health (GH), physical functioning (PF), role-physical (RP), bodily pain (BP), vitality (VT), social functioning (SF), role-emotional (RE), and mental health

(MH). Score of Physical Component Summary (PCS) is obtained from GH, PF, RP, and BP. Score of Mental Component Summary (MCS) is obtained from SF, RE, MH, and VT. The SF-12 summary scores (PCS and MCS) range from 0 to 100, with higher score representing better self-reported health. The Chinese version of the SF-12 demonstrates good reliability and validity [21].

Supportive Care Needs Survey Short Form (SCNS-SF34)

SCNS-SF34 [22] measures patients' perceived need strength on 34 needs classified into five domains: physical and daily living (5 items), psychological needs (10 items), patient care and support (5 items), health system and information (11 items), and sexuality needs (3 items). Patients were asked to rate each of these 34 needs for the previous month using a 5-point Likert scale (need strength): 1—no need: not applicable; 2—no need: satisfied; 3—low need; 4—moderate need; and 5—high need. Higher scores reflect greater unmet need strength. The Chinese version of the SCNS-SF34 was used and demonstrated good reliability and validity [23].

Posttraumatic growth inventory (PTGI)

The PTGI is a 21-item, self-rating instrument for assessing positive outcomes reported by persons who have experienced traumatic events. The scale includes the factors' new possibilities, relating to others, personal strength, spiritual change, and appreciation of life. The Cronbach α is 0.90 for the total score [24]. A reliable Chinese version of the PTGI has recently been validated [25].

Analysis

Content validities of SIS and IPM were assessed in 202 patients who had just completed PRISM-R2. The patients were asked to write about why they chose the specific size of the illness disk and placed it at the spot of their choosing. The

content analysis was used to analyze these comments [26]. All data obtained from the questionnaires were analyzed using the Statistical Package for Social Sciences (SPSS) version 16.0 (IBM SPSS Inc., Armonk, New York, USA). Descriptive analysis included the means and standard deviations of the main variables. Analyses of variance (ANOVAs) were used to examine the differences on IPM of PRISM-R2 in the socio-demographic or clinical data such as age at diagnosis, time since diagnosis, gender, marital status, and education. Convergent validity of the PRISM-R2 assessed by calculating mutual Pearson's correlation coefficients between SIS, IPM, DT, SF-12, PTGI, and supportive care needs. Correlations above 0.5 were considered strong and correlations lower than 0.3, weak [27].

Results

Three hundred thirty-eight patients with DTC who were receiving the therapy of radioactive for remnant ablation completed the investigation. Two hundred two of the participants wrote why they chose the specific size of the illness disk and placed it at the spot of their choosing. Socio-demographic and clinical differences associated with the IPM were not found. The participants' characteristics and the results of ANOVAs between the IPM groups are shown in Table 1.

Content validity

Table 2 presents the typical examples of patients' comments both for low and high SIS scores (i.e., overlapping or not overlapping self and illness disks), and Table 3 presents the typical examples of patients' comments both for low and high IPM scores. Four themes emerged from the patients' comments regarding SIS: (1) impact of the DTC on daily life, (2) impact of DTC on self, (3) perceived response of others to DTC, and (4) perceived the positive changes caused by DTC. Themes 1 and 2 were reported most frequently. In general, low-scoring SIS respondents (i.e., more overlaps between self and illness disks) stressed the interference with daily life whereas high-scoring SIS patients experienced little interference with daily life. For low-scoring SIS patients, what distressed them most was that they cannot fulfill the duty of caring for their parents and children because of DTC. Additionally, patients with the high or low SIS experienced the positive changes as a result of the struggle with DTC, such as more cherishing life or changing unhealthy lifestyle.

Patients' comments on IPM could be categorized into four themes: (1) severity of the thyroid cancer, (2) impact of the thyroid cancer on daily life, (3) how to coexist with the DTC, and (4) perceived response of others to DTC. Patients with high IPM scores (i.e., chose the larger illness disks) typically reported that the disease was a severe problem for them and

had a great impact on several aspects of life. The young female patients expressed more worries. They worried the DTC would affect their marriage, childbirth, and their ability to look after the parents or children in the future. Low-scoring IPM patients regarded their medical problem as being relatively small, not interfering with daily life. Patients who chose the middle-sized illness disk stated that their disease had a moderate impact on daily life. Persons who chose the large illness disk feared in the future more, while individuals who selected the smaller disks expressed their confidence in overcoming the DTC (see Table 3).

Although Tables 2 and 3 show just 16 case vignettes, exactly the same themes come up consistently in all the patients' account.

The PRISM-R2

Patients were able to complete the PRISM-R2 task without difficulty, and it was clearly acceptable to them. Within the whole sample, the SIS ranged from 0 to 105 mm (mean 38.36, SD 22.2). Only one participant placed their illness disk (against the instructions) outside of the circle labeled as my life.

The majority of the participants ($n = 138$, 40.82%) chose the smallest illness disk (IPM = 1) to symbolize the perceived impact of their former cancer disease; 112 (33.14%) chose the medium disk (IPM = 2), whereas 88 (26.03%) chose the largest disk (IPM = 3).

The association between SIS and IPM was found to be moderate ($r = -.482$; $P < 0001$) and indicated that smaller IPMs were generally associated with larger SISs and vice versa. No differences were found between two variables of PRISM-R2 with the socio-demographic characteristics.

Convergent and divergent validity

Table 4 presents the descriptive statistics and correlations between (1) the PRISM-R2 variables (SIS and IPM) and DT, (2) the PRISM-R2 variables (SIS and IPM) and the PTG scales, (3) the PRISM-R2 variables (SIS and IPM) and SF-12 scales, (4) the PRISM-R2 variables (SIS and IPM) and SCNS-SF34 scales, and (5) SIS and IPM.

Correlations indicate that SIS was positively correlated with one subscale of PTGI (Personal strengthen) and two subscale of SF-12 (role emotional, social functioning). In contrast, SIS was negatively associated with three subscales of SF-12 (general health and mental health) and two subscales of SCNF-SF34 (physical and daily living needs and psychological needs). In addition, SIS was also negatively related with DT ($r = -.443$, $p < 0.01$)

The significantly positive associations between IPM and (1) DT ($r = .589$, $p < 0.01$), (2) two subscales of SF-12 (General health and vitality), and (3) all subscales of SCNS-

Table 1 Socio-demographic and clinical description for the whole sample and separated by IPM; comparisons of differences in distributions between the IPM groups ($N = 338$)

Variables	Small disk ($n = 138$) Mean (SD), N (%) Range	Medium disk ($n = 112$) Mean (SD), N (%) Range	Large disk ($n = 88$) Mean (SD), N (%) Range	F	p	Whole sample Mean (SD), N (%)
Age (years)	42.46(11.42) 18–73	38.69(9.4) 20–62	42.18(11.40) 24–70	2.155	.119	41.14(10.87)
Age at the diagnosis (years)	41.39(11.57) 18–72	37.09(9.2) 20–61	41.04(11.44) 22–69	2.795	.064	39.87(10.92)
Time since diagnosis (years)	1.38(2.38) 0.3–20	1.91(2.13) 0.5–15	1.43(1.48) 0.5–10	1.078	.343	1.57(2.10)
Gender				.131	.877	
Male	42(30.4)	38(33.9)	26(29.5)			106(31.4)
Female	96(69.6)	74(66.1)	62(70.5)			232(68.6)
Marital status				2.031	.134	
Single	14(10.1)	24(21.43)	4(4.5)			42(12.4)
Partner	124(89.9)	88(78.57)	84(95.5)			296(87.6)
Educational level				.658	.519	
Low	40(29.0)	16(14.3)	20(22.7)			76(22.5)
Medium	34(24.6)	42(37.5)	26(29.5)			102(30.2)
High	64(46.4)	54(48.2)	42(47.7)			160(47.3)
Number of surgical treatment				.712	.492	
1	104(75.4)	84(75)	68(77.3)	75.0		256(75.7)
2	34(24.6)	20(17.9)	20(22.7)	17.9		74(21.9)
≥ 3	0	8(7.2)	0			8(2.4)
Number of RAI treatment				1.714	.183	
1	126(91.3)	90(80.4)	72(81.8)			288(85.2)
2	10(7.2)	18(16.0)	16(18.2)			44(13)
≥ 3	2(1.4)	4(3.6)	0			6(1.8)

SF34 were found. Four subscales of SF-12 were negative correlated with IPM. At last, a moderately negative correlation between SIS and IPM was found ($r = -.482$, $p < 0.01$).

Discussion

The PRISM is regularly used for assessment of suffering in inpatient and outpatient settings and has been validated in many patient populations [14, 28–30]. However, to date, it has not been adopted for use in Chinese-speaking settings. The aim of the present study was to evaluate the validity of the PRISM-R2 as a measure of suffering in people with DTC in mainland China. Previous studies examining the PRISM's characteristics have found that it is generally well accepted and understood, even when different formats or versions are employed [14]. These results were supported by our findings. This article provided results of a preliminary validation of the PRISM-R2, which was probably used in assessing the suffering of patients with thyroid cancer in Eastern culture.

Based on the cultural differences between the east and the west, the content validity of PRISM-R2 was examined. SIS was intended to measure the perceived relationship between the patient's self and the illness, which served as an indicator of suffering, so the qualitative SIS data centered mainly on the thyroid cancer's impact on daily life and the self. For patients' SIS, a whole or partial overlap of the illness disk with self showed a high level of suffering. In our study, the biggest distress for the subjects with low-scoring SIS was their inability to fulfill the duty of caring for their parents and children. It could be interpreted in the background of China. Most patients with thyroid cancer are young-middle aged and the only child of the family. Diseases usually led to the decline in their social and family function. IPM was intended to measure the patients' perception of the magnitude or severity of the illness. In our study, participants' responses focused more on the patients' perception about the disease, and how they coped with the disease, such as leaving the stressor as it was, or tried to deal with the disease and its consequences better.

In order to examine the PRISM-R2's criterion validity, correlation was conducted with one instrument that measure close concepts, the distress thermometer. The DT is a modified

Table 2 Examples of patient comments on choice for positioning the self disk (Self Illness Separation [SIS])

Theme	Comment	SIS (mm)	Comment	SIS (mm)
	(SIS < 52 mm, overlap with self)		High SIS score (SIS > 52 mm, no overlap with self)	
Impact of thyroid cancer on daily life	I worry about the risk of surgery. I am the only son of the family, and have to take care of my parents. I'm so regretful that there are so many things in my life that haven't been done.	0	I was diagnosed with the thyroid cancer for 15 years. Now my only child has married. I have nothing to worry about.	75
Impact of thyroid cancer on self	Disease has changed my life. It affected me too much. It's too difficult for me to accept it.	0	Disease is nothing for me. I can live as healthy people. My positive attitude affected my family, and they all encouraged me.	90
Perceived response of others to thyroid cancer	The name "thyroid cancer" makes people look at me with disdain. I feel uncomfortable for this. It also burdens my family, but I can hide it.	13	Though I was diagnosed with thyroid cancer, I still think life is wonderful. After 68 all, so many lovers and relatives care about me and encourage me.	68
Perceived the positive changes caused by thyroid cancer	Disease-related experience made me cherish life more. Now, I force myself to do exercise and encourage myself to pursue real things what make me happy.	25	In my opinion, the disease made my life more positive. It changed my lifestyle in some degree.	72

Table 3 Examples of patient rationale for their choice of illness disk size (Illness Perception Measure [IPM])

Theme	Large illness disk	Medium illness disk	Small illness disk
Severity of the thyroid cancer	When I heard that I was diagnosed with the most horrible and ruthless cancer, I felt that I was not far from death. I thought that my life was coming to an end soon.	It is not big enough to affect my life but not small. I feel as if I live with a time bomb.	It is the lightest and the mildest of all cancers. It is unfortunate lucky for me since it does not affect my life. I do not need to worry about it at all.
Impact of the thyroid cancer on daily life	Disease affects my job, promotion, marriage, birth of child. The whole life has been changed.	I am not married and nor have children. As the only child of my parents, I am most worried about them. I love life, travel, and enjoy staying with my friends. Now, I can't continue my previous life, and the quality of my life has dropped.	I believe it can be cured completely. Everything went well since I was diagnosed with thyroid cancer.
How to coexist with the thyroid cancer	Cancer is just like a time bomb buried in my body; you don't know when it will outbreak. You have to pay timely attention to it.	Good attitude can overcome and defeat anything. Just keep happy every day and do not focus on negative aspects. I believe life will be better.	Since it is here, I should face it. Only by understanding the enemy can you defeat it. Beyond life and death, there is no big deal In terms of work and friends, I have not been much affected.
Perceived response of others to thyroid cancer	My parents are very worried about me. Colleagues joked that I was dying, and the leader wanted me to resign.	I was regarded as a patient in my colleagues' eyes because of frequently sick leave. Children showed great fear when they saw my neck scar.	Both my boss and colleagues understand and support me. I have nothing to worry about.

Patients chose the size of the disk on the basis of how much of an effect they believed their illness had on their lives

Table 4 Correlations of the SIS and IPM with DT, PTGI, SF-12, and SCNS-SF34 ($n = 338$)

Variables	Means	SIS	IPM
PRISM-R2			
SIS	38.36 ± 22.23	–	–.482**
IPM	1.85 ± 0.81	–.482**	–
DT	3.65 ± 2.14	–.443**	.589**
PTGI			
Related with others	12.67 ± 4.23	0.078	.080
New possibility	15.63 ± 6.38	–.032	–.023
Personal strength	15.79 ± 4.85	.217*	–0.23
Appreciation of life	15.69 ± 4.98	–.020	.100
SF-12			
General health	3.31 ± 0.97	–.258**	.336**
Physical functioning	5.02 ± 0.99	.102	–.147
Role-physical	2.95 ± 0.93	.131	–.215**
Bodily pain	2.69 ± 1.11	–.067	.003
Role-emotional	3.08 ± 0.95	.295**	–.317**
Mental health	6.85 ± 1.48	–.230**	.131
Vitality	2.95 ± 1.17	–.272**	.261**
Social functioning	3.49 ± 0.93	.112	–.227**
Physical Component Summary	53.29 ± 10.11	–.067	–.044
Mental Component Summary	49.38 ± 10.99	–.084	–.007
SCNS-SF34			
Physical and daily living needs	10.94 ± 4.46	–.143	.258**
Psychological needs	25.24 ± 9.52	–.318**	.425**
Sexuality needs	5.75 ± 2.84	–.119	.202**
Patient care and support needs	13.23 ± 4.73	–.135	.202**
Health system and information needs	36.47 ± 11.88	–.051	.268**

SIS Self-Illness Separation, IPM Illness Perception Measured: distress thermometer, PTGI posttraumatic growth inventory, SF-12 12-item Short-Form health survey, SCNS-SF34 the Supportive Care Needs Survey Short Form

* $p < 0.05$, ** $p < 0.01$

visual analogue scale ranging from 0 (no distress) to 10 (extreme distress) resembling a thermometer. It has been widely used to assess the distress caused by the disease, especially in patients with cancer. Our findings showed both IPM and SIS were moderately or strongly associated with DT, which is in line with Cassell's conceptualizations of suffering as a predominantly psychological construct [8]. Certainly, comparing with DT, the PRISM-R2 provided more interesting and relevant additional information on some important aspects of the patient's illness experiences.

Wittmann [31] confirmed that recognizing personal growth in response to the illness experience may reduce suffering. The capacity to find meaning in adversity is a key element of the posttraumatic growth [31]. In our qualitative analysis, even patients with lower SIS scores reported the positive changes caused by the disease. Some participants emphasized that they cherished the life more and their lifestyle was healthier than before. To understand the relationship between PRISM-R2 and PTGI, the correlation analysis between them

was conducted. A weak association between SIS and personal strength was found, which was consistent with PRISM being a measure of suffering.

In a previous validation study in chronically ill patients, higher SIS scores (indicating low suffering) were related to better symptom control, increased autonomy, and maintaining social and personal roles [12]. However, low SIS ratings (indicating severe suffering) were related to more illness interference with vital aspects of life, an essential aspect of the suffering experience. In our study, correlations between SIS and SF-12, and SCNS-SF34 were examined. As predicted, significant correlations with general health, role-emotional, mental health, and vitality were found. No relationships were found between the SIS and symptoms such as physical functioning and bodily pain. Patients in the severe suffering group did not show higher scores in physical symptoms, which perhaps indicated that symptom severity was not sufficient to cause suffering in this group. Additionally, the stronger correlation between SIS and psychological needs subscale of SCNS-SF34

was confirmed, while no correlations were found between the SIS and other subscales of support care needs. Our findings supported the view that suffering had been closely related to emotional distress [32]. As Wittmann [31] explains, “changes to the self resulting from the inability of a person’s attributes or coping mechanisms to adapt may lead to greater suffering.”

One literature [10] confirmed that patients with small illness disks proved to be comparable to the normative population with respect to health status. In our findings of content analysis, some patients who chose the small disk truly expressed that the thyroid cancer did not affect their life for it could be cured. The minority (26.03%) of the participants who chose the large disk reported significant fear about the health status, which was probably related with the perception of patients about the thyroid cancer. Correlations between IPM and SF-12, and SCNS-SF34 were examined. Indeed, IPM correlated more strongly with these measures than SIS. IPM showed minor or medium significant relationships with all the subscales of SCNS-SF34, which showed IPM was more prone to respond patient’s perception and needs about the disease. Patients who chose the small illness disks were more likely to accept and live with the thyroid cancer, and they were not likely to be characterized by severely deteriorated levels of wellbeing. On the other hand, patients choosing a medium or large illness disk were more likely in need of attention in clinical practice, and they showed more anxieties about the disease and unmet support care needs. Overall, small illness disks indicate low levels of suffering and need no or little clinical attention while medium and especially large illness disks should get more concern since they can be interpreted as indicating extra needs for attention and support [10].

Clinical implication

On a clinical level, this research has some implications for health-care providers. Firstly, alleviation of suffering is widely regarded as one of the main objectives of health care. Effectively assessing the patients’ suffering is the first step to provide high-quality health service for them. PRISM-R2 is a brief instrument and very easy to administer, and it is very well accepted by patients. Secondly, in the PRISM-R2, placing the self in the middle of one’s living environment makes interpretation for the patient easier to understand. By offering a test without specific questions, the PRISM-R2 may evaluate individually determined, implicit aspects of suffering and illness severity, which may be useful to guide or evaluate the interventions for patients. The findings suggest that patients with high IPM and low SIS need special attention from health-care providers. Our study supports that the patients with low SIS have more psychological needs. While patients with large IPM more focused on the disease and its consequence, and they are

eager to get more supportive care. Suffering prevention and early treatment is central to quality patient care. We hope PRISM-R2 will be useful for clinicians and researchers in search for the alleviation of the patients’ suffering.

Limitation

Our study had some noteworthy limitations. First, this study just tested the content validity and convergent and divergent validity. Future research is needed to obtain insights into the cognitive processes and considerations that result in the decision why to select a septic illness disk and where to place it, in order to examine this instrument’s construct validity. Secondly, this study just tested the validity of PRISM-R2 in the patients with thyroid cancer, if it is suitable to assess the patients with other types of cancer needs further study. Thirdly, our findings found that the SIS had a negative correlation with the psychological needs of patients, and IPM had positive correlations with all the subscales of the unmet supportive care needs. Further longitudinal study is needed to confirm whether patients’ suffering will be alleviated if their unmet supportive care needs are improved.

Conclusion

The PRISM-R2 might be a feasible and valid instrument to capture aspects of thyroid-related suffering in Chinese backgrounds. Its relationships with quality of life and supportive care indicate that it is worthwhile to use in the clinical settings. Additionally, the PRISM-R2 is easily administered and offers a good starting point for clinical conversations. It can help the patients to see the illness as a separate “thing,” not covering over the person and his/her life which help the patients to handle the illness by putting it to a place and learn to live with the thyroid cancer.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflicts of interest.

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References

- Cooper DS, Doherty GM, Haugen BR (2009) Revised American Thyroid Association management guidelines for patients with thyroid nodules and differentiated thyroid cancer. *Thyroid* 20(8):942–942
- Taieb D, Baumstarck-Barrauk K, Sebag F (2011) Health-related quality of life in thyroid cancer patients following radioiodine ablation. *Health Qual Life Out* 9:33
- Massolt ET, Vander WM, Korevaar TM, Kam BLR, Burger JW (2016) Thyroid hormone and its metabolites in relation to quality of life in patients treated for differentiated thyroid cancer. *Clin Endocrinol* 85(5):781–788
- Applewhite MK, James BC, Kaplan SP, Angelos P, Kaplan EL, Grogan RH, Aschebrook-Kilfoy B (2016) Quality of life in thyroid cancer is similar to that of other cancers with worse survival. *World J Surg* 40(3):551–561
- Banach R, Bartès B, Farnell K, Rimmele H, Shey J, Singer S, Verburg FA, Luster M (2013) Results of the thyroid cancer alliance international patient/survivor survey: psychosocial/informational support needs, treatment side effects and international differences in care. *HORMONES* 12(3):428–438
- Roerink SH, de Ridder M, Prins J, Huijbers A, de Wilt HJ et al (2013) High level of distress in long-term survivors of thyroid carcinoma: results of rapid screening using the distress thermometer. *Acta Oncol* 52(1):128–137
- Hirsch D, Ginat M, Levy S, Benbassat C, Weinstein R, Tsvetov G, Singer J, Shraga-Slutzky I, Grozinski-Glasberg S, Mansiterski Y, Shimon I, Reicher-Atir R (2009) Illness perception in patients with differentiated epithelial cell thyroid cancer. *Thyroid* 19(5):459–465
- Cassell E (1991) The nature of suffering. In: *The nature of suffering and the goals in medicine* edited by: Cassell EJ. Oxford University Press, New York, pp 31–47
- Cassell E (1999) Diagnosing suffering: a perspective. *Ann Intern Med* 131(7):531–534
- Lehmann V, Oerlemans S, van de Poll-Franse LV (2011) Suffering in long-term cancer survivors: an evaluation of the PRISM-R2 in a population-based cohort. *Qual Life Res* 20(10):1645–1654
- Büchi S, Sensky T, Sharpe L (1998) Graphic representation of illness: a novel method of measuring patients' perception of the impact of illness. *Psychother Psychosom* 67:222–225
- Büchi S, Buddeberg C, Klaghofer R (2002) Preliminary validation of PRISM (Pictorial Representation of Illness and Self Measure)—a brief method to assess suffering. *Psychother Psychosom* 71(6):333–341
- Lima-Verde AC, Pozza DH, Rodrigues LL (2013) Cross-cultural adaptation and validation for Portuguese (Brazilian) of the Pictorial Representation of Illness and Self Measure instrument in orofacial pain patients. *J Orofac Pain* 27(3):271–275
- Krikorian A, Limonero JT, Vargas JJ, Palacio C (2013) Assessing suffering in advanced cancer patients using Pictorial Representation of Illness and Self-Measure (PRISM), preliminary validation of the Spanish version in a Latin American population. *Support Care Cancer* 21(12):3327–3336
- Wouters EJ, Reimus JL, van Nunen AM, Blokhhorst MG, Vingerhoets AJ (2008) Suffering quantified? Feasibility and psychometric characteristics of 2 revised versions of the Pictorial Representation of Illness and Self Measure (PRISM). *Behav Med* 34(2):65–78
- Liu Y, Zhang S, Chen W (2012) Trend of incidence and mortality on thyroid cancer in China during 2003–2007. *Chin. J Epidemiol* 33(10):1044–1048
- Husson O, Haak HR, Oranje WA, Mols F, Reems PH (2011) Health-related quality of life among thyroid cancer survivors: a systematic review. *Clin Endocrinol* 75(4):544–554
- Pincus T, Morley S (2001) Cognitive-processing bias in chronic pain: a review and integration. *Psychol Bull* 127(5):599–617
- Gessler S, Low J, Daniells E, Williams R, Brough V, Tookman A, Jone L (2008) Screening for distress in cancer patients: is the distress thermometer a valid measure in the UK and does it measure change over time? A prospective validation study. *Psycho-Oncol* 17:538–547
- Zhang N, Zhang W, Song L (2010) Application of the NCCN distress thermometer in Chinese cancer patients. *Chin Ment Health J* 24(12):897–901
- Shou J, Ren L, Wang H, Yan F, Cao X, Wang H, Wang Z, Zhu S, Liu Y (2016) Reliability and validity of 12-item Short-Form health survey (SF-12) for the health status of Chinese community elderly population in Xujiahui district of Shanghai. *Aging Clin Exp Res* 28(2):339–346
- Boyes A, Girgis A, Lecathelinais C (2009) Brief assessment of adult cancer patients' perceived needs: development and validation of the 34-item supportive care needs survey (SCNS-SF34). *J Eval Clin Pract* 15(4):602–606
- Au A, Lam WWT, Kwong A, Suen D, Tsang J, Yeo W, Suen J, Ho WM, Yau TK, Soong I, Wong KY, Sze WK, Ng A, Girgis A, Fielding R (2011) Validation of the Chinese version of the Short-Form Supportive Care Needs Survey Questionnaire (SCNS-SF34-C). *Psycho-Oncol* 20(12):1292–1300
- Calhoun LG, Tedeschi RG (1996) The posttraumatic growth inventory: measuring the positive legacy of trauma. *J Trauma Stress* 9(3):455–471
- Wang YB, HB W, Liu XH (2013) Prevalence and predictors of posttraumatic growth in accidentally injured patients. *J Clin Psychol Med Settings* 20(1):3–12
- Elo S, Kyngäs H (2008) The qualitative content analysis process. *J Adv Nur* 62(1):107–115
- Cohen J (1988) *Statistical power analysis for the behavioral sciences*. Psychology Press, New Jersey
- Fotiou K, Hofmann M, Fotiou K, Kaufmann R, Thaci D (2015) Pictorial Representation of Illness and Self Measure (PRISM): an effective tool to assess the burden of psoriasis. *J Eur Acad Dermatol Venereol* 29(12):2356–2362
- Kassardjian CD, Gardner-Nix J, Dupak K, Barbati J, Lam-McCulloch J (2008) Validating PRISM (Pictorial Representation of Illness and Self Measure) as a measure of suffering in chronic non-cancer pain patients. *J Pain* 9(12):1135–1143
- Peter N, Kleinjung T, Horat L, Schmidt-Weitmann S, Meyer M (2016) Validation of PRISM (Pictorial Representation of Illness and Self Measure) as a novel visual assessment tool for the burden of suffering in tinnitus patients. *Health Qual Life Out* 14:47
- Wittmann L, Sensky T, Meder L, Michel B, Stoll T (2009) Suffering and posttraumatic growth in women with systemic lupus erythematosus (SLE): a qualitative/quantitative case study. *Psychosomatics* 50(4):362–374
- Wilson K, Amir Z (2008) Cancer and disability benefits: a synthesis of qualitative findings on advice and support. *Psycho-Oncol* 17(5):421–429