Original Article

Cancer Illness Perception and Self-Management of Chinese Patients

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ABSTRACT

Objective: The purpose of this article is to examine the relationships of illness perception, self-care, self-efficacy, and self-care strategies and their effects on Chinese cancer patients' quality of life (QOL). **Methods:** Questionnaires include data on demographic characteristics, illness perception, symptom self-care activity, and QOL. A secondary analysis was conducted on a sample of ethnic Chinese breast-and-colon cancer patients (n = 159) to examine multivariate associations. Descriptive statistics, bivariate correlational analysis, and hierarchical regression analysis were used to analyze quantitative data. **Results:** The hierarchical regression model explained 43% of variance in QOL. Perceived illness consequence, personal control, and performance functioning status were found to be significant predictors in the model. Comparisons between breast-and-colon

cancer patients showed that colon cancer patients significantly perceived higher levels of chronicity and negativity toward cancer than breast cancer patients. Conversely, breast cancer patients had significantly higher level of QOL and efficacy in making decision. Stress and overwork were the common perceived causes of cancer reported by these patients. Conclusions: These findings suggest that improving self-care efficacy and positive personal control can improve Chinese cancer patients' QOL. Variation in illness perceptions of cancer by different types of cancer should be considered in cancer survivorship planning and patient education.

Key words: Culturally competent care, illness perception, psychometric equivalence, self-management

Introduction

Cancer is the leading lifelong disease that affects people globally. It is a leading cause of morbidity and mortality worldwide, with approximately 14 million new cases. The disease accounted for 8.2 million deaths globally in 2012. The number of new cases is expected to rise by about 70% over the next two decades. More than 60% of

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the world's total new annual cases occur in Africa, Asia, and Central and South America.^[1] Cultural backgrounds can influence patients' health belief and behaviors, such as how they perceive the disease, how they self-manage their health and disease process, and what resources they

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choose to use to cope with their illness.[2-5] Although cancer treatment and public knowledge about cancer have been made widely available in most developed countries, in some communities, people with cancer are still stigmatized. Delay or lack of appropriate health-seeking and self-management behaviors persists among some patients with different cultural backgrounds. [6-12] Patients' self-management is imperative to reduce possible complications and maintain treatment completion, symptom control, collaboration with health-care professionals, and quality of life (QOL) for patients with chronic illnesses.^[13,14] The current literature supports the need for cancer patients to engage in self-management to help decrease side effects, symptoms, and psychological burdens of the disease and its treatments. [15,16] Increasingly, cancer care is being done on an outpatient basis, thus reducing hospital stays. This trend requires that patients actively engage in their treatment to minimize symptoms and complications. Ineffective self-management can lead to detrimental outcomes, such as unnecessary hospital readmission, worsened morbidities, decreased QOL, and increased health-care costs.

Chinese is the world's most common language ranked among first-language speakers.[17] Cancer has been the leading cause of death in ethnic Chinese.[1] In studies among ethnic Chinese cancer patients, fear of cancer and avoidance of discussing the disease among patients had been reported. [7] Although Chinese cancer patients reported multiple distressing symptoms, it has been found that only a few self-care activities were reported by Chinese patients to manage their symptoms. Low-to-moderate levels of QOL were also reported in Chinese cancer patients.[18] The disengagement in active self-care could be influenced by how cancer is perceived due to patients' cultural and societal beliefs about the disease. Providing culturally sensitive health care requires a better understanding of the impact of cancer on various cultural subgroups and how these groups cope with the disease. As cancer has become a top disease impacting Chinese globally and cancer treatment has gradually moved to ambulatory basis, it is imperative to examine factors affecting Chinese patients' self-management practice and QOL. Furthermore, how cancer patients engage their self-management may be different among patients with different types of cancers. [2,3,5] Previous studies have primarily emphasized on illness representation of breast cancer patients^[2,4,5] or self-management in single type of cancer (e.g., breast cancer). [6,12,15,18,19] However, there is little research to examine the interrelationships among cancer patients' illness perception, self-management practice, and QOL, and if there are differences among patients with different cancer diagnoses. The goal of this article is to explore and examine the predicted variance of illness perception and self-management practice to the QOL in a sample of ethnic Chinese patients with breast-and-colon cancers. Breast-and-colon cancers were selected in this study as they are the top prevalent cancers in Chinese people and they represent different disease course and cancer progression. A comparative analysis was also made to explore the differences in illness perception, self-care activities, self-efficacy, and QOL between breast-and-colon cancer patients. The study findings will support future methods of engaging with Chinese patients to increase the levels of self-care and QOL. In addition, the results contribute to our understanding of illness adjustment and survivorship reported by ethnic Chinese cancer patients.

Methods

Sample/setting

A secondary analysis was conducted on a cancer project which recruited breast-and-colon cancer patients in the northern region of Taiwan. The sample was from the infusion unit and inpatient cancer unit of a major metropolitan medical center in northern region of Taiwan from May 2011 to May 2012. The inclusion criteria included: (1) adult cancer patients (age ≥21 years); (2) primary medical diagnosis of breast or colon cancer; and (3) ability to speak or read Chinese. All participants were receiving active treatments during the data collection period.

Ethical approval

The study was conducted in accordance with the Declaration of Helsinki and was approved by the Institutional Review Board. Informed written consent was obtained from all participants prior to their enrollments in this study.

Procedure

Eligible participants were invited to participate in the study while they visited the medical facility for their treatments. After consenting to be a part of the study, each participant was asked to complete the study questionnaire booklet. The booklet, provided in traditional Chinese written characters, included an established questionnaire and scales covering demographics, illness perception, self-management practice, and QOL. The study materials and consent forms were translated by forward and backward translation methods to achieve linguistic congruence. All the study questionnaires have been used in a prior study with a Chinese-speaking sample population. Before the questionnaire booklet was provided to the study participants, it was reviewed by five local healthy volunteers to confirm

its clarity and validity. Participants were asked to complete the questionnaire by themselves. Research assistants who were fluent in Mandarin Chinese and familiar with local Chinese slang medical terms were available onsite to answer the questions. It took about 30 min for the participants to complete the questionnaire booklet.

Instruments

Demographic characteristics

Questions about demographic characteristics included common demographics such as age, gender, education, marital status, working status, and income. Current medical history and treatment were also included. Karnofsky's scale was included to assess participants' functional status.

Illness perception

The existing Chinese-Traditional version of the revised Illness Perception Questionnaire (IPQ-R) was used to measure how patients perceived their cancer. The validity and reliability of the IPQ-R have been established in patients with various medical conditions. [20] The subscales of IPQ-R include identity, timeline, consequences, personal control, treatment control, illness coherence, timeline cyclical, emotional representations, and causes. The identity subscale measured the belief about the number of symptoms attributed to the illness. The other subscales were measured by a 5-point Likert scale. The internal consistency reliability (Cronbach's alpha coefficients) of these subscales ranged from 0.75 to 0.88 in this study sample.

Self-management practice

The aspects of self-care efficacy, symptom self-care activity, and health maintenance resources were recorded. Self-care efficacy was measured with the scale of Strategies Used by People to Promote Health to assess the level of confidence in doing self-care activities in cancer patients. [19] The subscales included positive attitude, stress reduction, and making decisions. The internal consistency reliability of the total scale was 0.98 in this sample. The internal consistency reliability of subscales (positive attitude, stress reduction, and making decisions) was 0.95, 0.96, and 0.93, respectively.

Symptom self-care activity was measured with a self-care diary to record the use and effectiveness of self-care activities. The scale included a list of self-care activities for 16 symptoms and a 6-point scale to rate the effectiveness of the activities in the past 3 days. [21] Each page contained self-care activities for one type of symptom. Therefore, if participants did not report certain symptoms, they did not need to fill out the self-care activity for that symptom and they were instructed to proceed to the next page. Three open-ended questions were developed in the study to assess

the aspect of health maintenance resources. The questions included: "What do you do daily to take care of yourself due to cancer?" "Where do you learn these resources?" and "Are these resources helpful?"

Quality of life

The QOL was measured with the 33-item Quality of Life Scale (Multidimensional Quality of Life Scale for Cancer [MQOLS-CA]). The MQOLS-CA is a cancer-specific QOL measure, with each item scored on a numeric rating scale from 0 to 10. The total average score indicates the level of QOL perceived by patients with cancer. [22,23] The alpha reliability of 0.91 was reported in breast cancer patients. [15] The internal consistency reliability of the total scale was 0.75 in this sample.

Statistical analysis

The data included quantitative data from rating items and qualitative data from open-ended questions. All participants reported their original data in traditional Chinese and all original data were entered into the SPSS® 23.0 statistical software. [24] Since all original data were in traditional Chinese, two bilingual research assistants assisted in the double data entry process. One person entered the original data in Chinese into the SPSS software, and then the other person translated the open-ended responses into English in the SPSS. The researcher and research assistants then reviewed all data again by comparing with each original study questionnaire to ensure the accuracy of data entry. This process ensured the data accuracy between data entry in forward and backward translation processes. The dataset was further cleaned through descriptive and frequency analysis repeatedly. Statistical significance was preset as $\alpha = 0.05$. Bivariate analysis, comparative statistics, and heretical regression model were used to analyze the associations and differences among illness perception, self-care activities, self-care efficacy, and QOL. Content analysis technique was used to analyze the qualitative responses from open-ended questions.

Results

Demographic characteristics of sample

The mean age of the sample was 55.55 years (standard deviation [SD] = 10.39), and 83% were female. Fifty-one percent of the participants had college level and above of education. Twenty-one percent worked full time when they enrolled in the study. The average Karnofsky's score (KFS) was 78.43 (SD = 13.19). Seventy-two percent of the participants reported their religious preference as Buddhism or Taoism. Thirty-three percent identified themselves as the primary caregiver. Income, primary caregiver

position, staging status, age, and KFS were found to be statistically different between patients with breast-and-colon cancers. There was a higher proportion of colon cancer patients who reported that they did not have any income (61% in colon vs. 33% in breast, $\chi^2 = 16.38_{(5)}$, P < 0.05). In addition, there was a higher percentage of colon cancer patients who were in Stage 4 diagnosis during the study period (76% in colon vs. 19% in breast, $\chi^2 = 53.58_{(3)}$ P < 0.05). In comparison, a higher proportion of breast cancer patients identified themselves as the primary caregiver (44% in breast vs. 13% in colon, $\chi^2 = 15.59_{(1)}$, P < 0.05). The average age of colon cancer patients was 59.94 years (SD = 10.75), which was statistically higher than the average age as 53.24 years (SD = 9.46) of breast cancer patients ($t_{(155)} = 4.02$, P < 0.001). The average KFS of colon cancer patients (72.78 [SD = 12.20]) was significantly lower than the average score of breast cancer patients (81.33 [SD = 12.79], $t_{(157)} = 4.06$, P < 0.001). There was no statistical difference found in other demographic characteristics between the breast-and-colon cancer patients.

The overall sample reported moderate levels of QOL (M = 6.12, SD = 0.92) and self-care efficacy (M = 86.05, SD = 29.33). On an average, approximately five symptoms were reported.

Comparisons between breast-and-colon cancer patients

The main study variables were compared between breast-and-colon cancer subgroups to examine if there were any statistically significant differences [Table 1]. The analysis showed that there were statistical differences found in IPQ timeline ($t_{(152)} = 4.10, P < 0.001$), IPQ consequence $(t_{(153)} = 3.51, P < 0.01)$, IPQ illness coherence $(t_{(153)} = 2.22,$ P < 0.05), making decision efficacy ($t_{(145)} = 2.15$, P < 0.05), and QOL ($t_{(155)} = 3.96$, P < 0.001). Overall, colon cancer patients significantly perceived higher levels of chronicity and negativity toward cancer than breast cancer patients. However, colon cancer patients reported a better understanding of their own cancer conditions. Still, breast cancer patients had a significantly higher level of QOL and efficacy in making decision [Table 1]. In terms of the possible causes of illness reported by the participants, the top five selected causes among breast cancer patients were stress/worry, diet/eating habits, family problems and worries, overwork, and emotional state/feeling down. The top five selected causes among colon cancer patients were diet/eating habits, stress/worry, chance/bad luck, own behaviors, and overwork.

The overall sample reported moderate levels of QOL (M = 6.12, SD = 0.92) and self-care efficacy (M = 86.05, SD = 29.33). On an average, approximately five symptoms were reported from the self-care diary. The top five reported symptoms among breast cancer patients were fatigue, hair loss, numbness in limbs, taste change, and difficulty in sleep. The top five symptoms reported among colon cancer patients were fatigue, numbness in limbs, taste change, loss of appetite, and difficulty in sleep. On an average, 16 self-care strategies were selected on the self-care diary for symptom management (M = 15.75, SD = 13.81). In the question of "What do you do daily to take care of yourself

Variable	Breast $(n=105)$		Colon $(n=54)$		Total $(n=159)$		
	Mean	SD	Mean	SD	Mean	SD	Range
Illness perception							
Identity (number of perceived symptoms related to illness)	3.33	3.23	3.96	3.05	3.55	3.18	0-16
IPQ timeline*	17.34	5.04	20.67	4.33	18.51	5.04	0-30
IPQ time cycle	8.89	3.52	9.35	3.10	9.05	3.38	0-17
IPQ consequence*	16.49	4.62	19.11	4.08	17.40	4.60	0-28
IPQ personal control	21.87	4.73	21.74	4.73	21.82	4.71	0-30
IPQ treatment control	18.64	4.62	17.93	3.14	18.39	3.30	4-25
IPQ illness coherence*	16.99	4.49	18.57	3.63	17.54	4.26	0-25
IPQ emotional representation	17.25	5.26	17.31	4.15	17.27	4.89	0-30
Self-care efficacy							
Positive attitude	53.17	15.00	48.81	17.17	51.56	15.92	16-80
Stress reduction	30.37	8.86	29.63	10.98	30.10	9.65	10-50
Making decision*	8.20	3.42	6.87	3.97	7.71	3.68	3-15
Total score	86.43	29.00	85.31	30.22	86.05	29.33	6-145
QOL*	6.32	0.89	5.74	0.84	6.12	0.92	3.48-8.95
Karnofsky's score*	81.33	12.79	72.78	12.20	78.43	13.19	50-100
Age*	53.24	9.46	59.94	10.75	55.55	10.19	29-79
Number of symptom reported	4.92	3.15	4.98	2.41	4.94	2.88	0-16
Number of self-care strategies reported	15.62	14.64	16.02	12.17	15.75	13.81	0-71

due to cancer?", the top five reported activities among breast cancer patients were exercise/walk (25%), changing diets (24%), rest/relax (9%), keeping positive (8%), and maintaining regular lifestyle (7%). Whereas, the top five reported activities among colon cancer patients were exercise/walk (25%), doing something enjoyable (17%), changing diets (15%), keeping positive (8%), and reading (7%). In the question of "Where do you learn these resources?", the top five reported resources of self-care among breast cancer patients were books/magazines/ brochures (24%), providers (21%), friends/relatives (18%), the Internet (11%), and myself (9%). The top five reported resources of self-care among colon cancer patients were myself (41%), friends/relatives (12%), books/magazines/ brochures (14%), providers (14%), and nothing (5%). In the question of "Are these resources helpful?", 65% of breast cancer patients reported yes and 61% of colon cancer patients reported yes.

Correlation analysis

The bivariate correlation analysis among the main study variables of illness perception, self-care efficacy, and QOL is summarized in Table 2. Between illness perception dimensions and QOL, there were moderate negative associations between QOL and timeline ($r_{(153)} = -0.36$, P < 0.001), time cycle ($r_{(152)} = -0.42$, P < 0.001), consequence ($r_{(154)} = -0.43$, P < 0.001), and emotional representation ($r_{(154)} = -0.32$, P < 0.001). Whereas, there were moderate positive associations between QOL, personal control ($r_{(153)} = 0.32$, P < 0.001) and treatment control ($r_{(153)} = 0.25$, P < 0.01). As for between self-care efficacy dimensions and QOL, there were moderate-to-high positive correlations between QOL and total efficacy ($r_{(157)} = 0.37$, P < 0.001), positive attitude ($r_{(146)} = 0.49$, P < 0.001), stress reduction ($r_{(148)} = 0.44$, P < 0.001), and making decisions ($r_{(147)} = 0.34$, P < 0.001).

Between illness perception dimensions and self-care efficacy, total self-care efficacy was moderately and negatively correlated with timeline ($r_{(154)} = -0.24$, P < 0.01), time cycle ($r_{(153)} = -0.34$, P < 0.001), consequence ($r_{(155)} = -0.29$, P < 0.001), and emotional representation ($r_{(155)} = -0.38$, P < 0.001). By comparison, there were strong positive associations between total self-care efficacy level and personal control ($r_{(154)} = 0.48$, P < 0.001), treatment control ($r_{(154)} = 0.48$, P < 0.001), and illness coherence ($r_{(155)} = 0.49$, P < 0.001).

Multiple regression analysis

Predicting quality of Life from demographic characteristics, illness perception, self-care efficacy, and self-care strategy

A four-stage hierarchical multiple regression was conducted with QOL as the dependent variable. Residual and scatter plots indicated that the assumptions of normality, linearity, and homoscedasticity were all satisfied. Demographic variables were entered at stage one of the regression to control for demographic characteristics. The dimension variables of illness perception subscale were entered at stage two, the total score of self-care efficacy was entered at stage three, and the average number of self-care strategies per symptom was entered at stage four [Table 3].

The hierarchical multiple regression analysis revealed that at stage one, demographic characteristics contributed significantly to the regression model ($F_{(9,127)} = 4.48$, P < 0.001) and accounted for 24% of the variation in QOL. In step two, adding the illness perception subscale dimension variables explained an additional 18% of the variation in QOL and this change in R^2 was significant (F Change_(8,119) = 4.46, P < 0.001). In step 3, adding self-care efficacy to the regression model only explained an additional 1% of the variation in QOL and this change in R^2 was not significant. However, the overall model

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13
Identify													
Timeline	0.26**												
Time cycle	-0.21**	0.43***											
Consequence	0.37***	0.63***	0.54***										
Personal control	0.00	-0.09	-0.23**	-0.01									
Treatment control	-0.10	-0.19*	−0.23**	-0.08	0.70***								
Illness coherence	-0.02	0.06	-0.21*	-0.04	0.49***	0.54***							
Emotional representation	0.18*	0.45***	0.40***	0.55***	-0.11	-0.08	-0.12						
Positive attitude	-0.06	-0.43***	-0.48***	-0.42***	0.48***	0.48***	0.42***	-0.53***					
Stress reduction	0.02	-0.34***	-0.39***	-0.34	0.44***	0.42***	0.47***	-0.52***	0.87***				
Making decision	0.06	-0.31***	-0.12	-0.35***	0.18*	0.19*	0.14	-0.31	0.55***	0.55***			
Total self-care efficacy	-0.03	-0.24**	-0.34***	-0.29***	0.48***	0.48***	0.49***	-0.38***	0.97***	0.95***	0.65***		
QOL	-0.09	-0.36***	-0.42***	-0.43***	0.31***	0.25**	0.12	-0.32***	0.49***	0.44***	0.34***	0.37***	

Table 3: Hierarchical regression analysis predicting quality of life							
Variable	ΔR^2	β					
Step 1							
Control variables ^a	0.24**						
Step 2							
Identity	0.18**	0.09					
IPQ timeline		0.02					
IPQ time cycle		-0.17					
IPQ consequence		-0.23*					
IPQ personal control		0.21*					
IPQ treatment control		-0.07					
IPQ illness coherence		-0.04					
IPQ emotional representation		-0.06					
Step 3							
Self-care efficacy (total score)	0.01	0.13					
Step 4	0.00						
Average self-care strategies used per symptom		-0.01					
Total R ²	0.43**						
n	136						

*P<0.05, **P<0.001, *Control variables included diagnosis, age, KPS score, education, religion, marital status, working status, income, number of symptom reported. IPQ: Illness Perception Questionnaire, KPS: Karnofsky Performance Scale

was statistically significant ($F_{(18,118)}=4.85$, P<0.001). Finally, the addition of average self-care strategies used per symptom to the regression model did not produce any numerical change in R^2 . The final model explained a total 43% of variance in Q ($F_{(19,117)}=4.56$, P<0.001). When all variables were included in stage four of the regression model, consequence ($\beta=-0.23$, P<0.05) and personal control ($\beta=0.21$, P<0.05) from the IPQ dimensions were found significant predictors of QOL. Among demographic characteristics, only KPS score had statistically significant predictor of QOL in the hierarchical regression model.

Discussion

The overall results showed that the proposed overall hierarchical model can explain 43% of the variance in QOL. Among all the entered blocks of variables, the categories of demographic variables and illness perception subscales accounted for most variance in the model. How these cancer patients perceived the disease consequences, their perceived personal control in the disease process, and their levels of functional status were the main predictors of QOL. This suggests that Chinese cancer patients who have a better physical functioning, who consider their cancer condition to have a positive outcome, and those that believe that they can have better personal control of the disease process have a better QOL.

From the comparative analysis between breast-and-colon cancer patients, the results showed that there were differences in demographic characteristics, illness perception, and self-care efficacy. In general, breast cancer

patients were significantly younger with better income status and functional status than the colon cancer patients in the study. In addition, breast cancer patients reported more positivity toward the disease consequence, QOL, and decision-making than the colon cancer patients. Whereas, both groups of patients selected similar top five possible perceived causes to their disease. The noticeable finding was that stress/worry and overwork were identified as one of the top reasons of cancer in this sample.

The bivariate correlation analysis showed that self-care efficacy subscales and illness perception subscales significantly correlated with each other. The higher level of overall self-care efficacy significantly correlated with lower levels of disease chronicity, cyclical pattern, perceived negativity, and emotional response toward cancer. Whereas, the higher level of overall self-care efficacy correlated significantly with higher levels of perceived control of cancer and treatment and coherent understanding of how cancer makes sense as a whole to the patients.

Fatigue was the top symptom reported by all participants. On an average, all participants reported using few strategies to manage their symptoms. The reported self-care information resources suggested that these Chinese cancer patients mostly used self-sought resources (books, magazines, brochures, the Internet, etc.) to seek information related to their daily self-care. Moreover, a higher proportion of breast cancer patients reported receiving information from their health-care providers than the colon cancer patients. Overall, the top reported daily self-care activity was exercise or walking.

Conclusion

The overall results from this study show that enhancing cancer patients' self-care efficacy and empowering patients to have positive personal control and attitude toward cancer and its treatment can significantly contribute to their QOL. While the sample was focused on Chinese patients in this study, the proposed predicted model can be applied to other populations. Although the importance of self-management in cancer patients' long-term QOL has been well established in the literature, [19,25] evaluating how patients perceive cancer differently based on their cultural and societal background can help support patients engage in self-management. As found in this study, illness perception has been supported to be the main covariate to QOL in cancer patients.^[26] Strategies and interventions can be employed to facilitate cancer patients for empowering their efficacy in self-management and active participation and planning for their adjustment in living with cancer. Further research can explore culturally appropriate interventions to assist Chinese cancer patients to support their self-management. Variation in illness perceptions of cancer by different types of cancer should be considered in cancer survivorship planning and patient education.

One intriguing finding from the study was that stress and overwork were commonly selected as the causes of cancer by these participants. Implementing strategies to maintain work—life balance and stress reduction at the societal structure and governmental policy level can be considered. Furthermore, the findings also suggest that most of these Chinese cancer patients engage in regular walking or exercise as a health maintenance strategy during their treatment. As supported in the literature, regular exercise and walking can help maintain physical functioning of cancer patients. The results of this study also show that functional status (KPS score) is a significant predictor of QOL. Health outcomes of different modes of exercise could be further explored in Chinese and other Asian cancer patients in future studies.

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Conflicts of interest

There is no conflict of interest.

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