

Symptoms, Self-Care, and Quality of Life of Chinese American Patients With Cancer

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Purpose/Objectives: To explore the cancer symptom experience, self-care strategies, and quality of life (QOL) among Chinese Americans during outpatient chemotherapy.

Design: Descriptive, exploratory cohort study.

Setting: An outpatient infusion unit at a public urban county medical center.

Sample: 25 Chinese-speaking patients with cancer completed the study. Participants were first-generation immigrants with low levels of acculturation; 88% could not read English; 64% had an annual household income of less than \$20,000.

Methods: Participants completed a basic demographics data sheet, the Suinn-Lew Acculturation Scale, the Memorial Symptom Assessment Scale and Self-Care Diary weekly for three weeks, and the Multidimensional QOL Scale-Cancer and Short-Form 36 Health Survey at the start and end of one chemotherapy cycle. Study instruments were translated into Chinese.

Main Research Variables: Symptoms, self-care, QOL, and acculturation.

Findings: Participants reported experiencing about 14 symptoms weekly. Lack of energy, hair loss, dry mouth, sleep difficulty, and loss of appetite were reported most frequently. On average, about two self-care strategies per symptom were reported and were low to moderate in effectiveness. About 20% of the sample listed Chinese medicine as part of their self-care strategies. A moderate level of QOL was reported.

Conclusions: Using translated standardized questionnaires can be a feasible method of data collection in studies with non-English-speaking patients. However, having well-trained, bilingual data collectors is important. More attention to long-term cancer self-management in minority patients with cancer is needed.

Implications for Nursing: Further research is needed with larger samples, more efficient community-based recruitment strategies, and the development and testing of culturally sensitive interventions.

As the United States continues to become increasingly diverse in races and cultures, more attention has been paid to studying healthcare experiences related to illness management in minority groups. Cancer is a leading health problem that affects millions of Americans every year and is the leading cause of death among Asian Americans (American Cancer Society, 2007), who are one of the fastest-growing ethnic groups in the United States. Chinese Americans, in particular, are the largest subgroup of Asian Americans; after Spanish, Chinese is the most widely spoken non-English language in the United States (U.S. Census Bureau, 2006). However, healthcare experiences and symptom management of Chinese Americans and Chinese immigrants remain largely unstudied. Language difficulties, sociocultural barriers, lack of knowledge, and inadequate resources may contribute to the disparity in healthcare research (Yu, 1986) and cancer research (Nguyen, Somkin, & Ma, 2005; Tu et al., 2005). Chinese and

Key Points . . .

- ▶ Although multiple symptoms are reported, few effective self-care strategies are used by Chinese American patients with cancer.
- ▶ Self-care activities can be culturally specific.
- ▶ Strategies to provide culturally appropriate education may improve cancer self-care in minority patients who do not speak English.

recent immigrants who are not yet proficient in English often do not participate in research and surveys (Ren & Chang, 1998). The absence of information on treatment morbidity, self-care practices, and experiences of symptom management could hinder healthcare providers in understanding healthcare needs among Chinese Americans during cancer treatment (Ren, Amick, Zhou, & Gandek, 1998). Patients who have particular cultural backgrounds may seek different types of self-management strategies; encounter bias and barriers in health care; have different expectations for cancer management as a result of cultural, social, and linguistic factors and established beliefs; and experience lack of knowledge or personal support (Kagawa-Singer, Wellisch, & Durvasula, 1997).

Symptom Management and Self-Care

As with chronic illnesses, cancer and its treatments can adversely affect patients' quality of life (QOL). Cancer is a chronic disease that significantly affects a person's physiologic, psychological, and social well-being. The symptoms and side effects from cancer and its treatments, such as chemotherapy, affect every aspect of QOL of patients with cancer (Dodd, Dibble, et al., 2001; Padilla & Grant, 1985). Current literature

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has concluded that patients with cancer and cancer survivors need to engage in self-management of side effects, symptoms, and psychological burdens of the disease and its treatments. For effective cancer symptom management, comprehensive collaboration is necessary among patients, their family members, and healthcare providers, as well as attention to patients' cultural and ethnic backgrounds. Although the pathophysiologic mechanism of cancer is believed to be fairly comparable across populations and ethnic groups, cultural beliefs and practices can affect cancer care and experiences along the entire disease continuum: prevention and early detection, treatment choices, management of side effects, psychosocial support, medical care use, and end-of-life care (Kagawa-Singer, 1998). Comprehensive assessments of symptom experience, self-care strategies to manage symptoms, and QOL also are part of culturally appropriate cancer care.

Several studies have documented the symptom experience and symptom characteristics in patients with cancer who experience multiple side effects and symptoms throughout the disease and treatment courses. Portenoy et al. (1994) documented the prevalence of 32 types of physical and psychological symptoms in patients with multiple cancer diagnoses (N = 216), ranging from 73% for lack of energy to 11% for difficulty swallowing. Dodd, Dibble, et al. (2001) reported that patients receiving cancer chemotherapy (N = 93) consistently experienced a constellation of pain, fatigue, and sleep disturbances. Patterns of symptoms and side effects accompanying cancer treatments also have been investigated. In the early 1980s, Dodd (1982, 1983) reported that side effects from cancer chemotherapy increased from week 4 to week 9 of treatment.

In addition to understanding patients' symptom experiences and QOL, knowing self-care strategies that patients use to manage symptoms and side effects is imperative for effective and appropriate symptom management planning. Dodd (1982) found that patients receiving chemotherapy (N = 48) reported an average of 7.69 side effects but only an average of 0.81 self-care behaviors. Side effects for which patients reported initiating self-care actions generally included symptoms whose remedies frequently were presented in the media or were general public knowledge. A subsequent study by Dodd (1983) showed that after being educated on side-effect management techniques, patients reported an increased use of self-care behaviors to manage the potential lethal side effects of infection and bleeding. Other studies (Dodd, 1984a, 1984b) have reported similar results of patients with cancer not initiating self-care behaviors. Those studies also showed that patients cited themselves as the most frequent source of information for self-care actions, followed by physicians and, lastly, nurses. Nail, Jones, Greene, Schipper, and Jensen (1991) investigated the symptoms and self-care efficacy of patients two days after they started chemotherapy (N = 49). The results showed that fatigue was the most prevalent symptom among 18 reported symptoms, and the most frequently used self-care strategies were taking naps and going to bed earlier than usual. The overriding conclusion from those studies was that patients with cancer require several self-care strategies to manage their illness experience, including multiple symptoms and side effects, and to maintain QOL. The description of self-care strategies reported by patients helps not only to indicate whether symptom management strategies are initiated ap-

propriately, but also to reveal more potentially effective and creative strategies developed by patients themselves.

Few studies have investigated the cancer symptom experience in ethnic minority groups. The Chinese American community, a mixture of recent immigrants and several generations of American-born individuals with strong ties to their cultural heritage, entails both extremes of socioeconomic and health indices. The cultural background of Chinese American patients may provide unique resources and behaviors in coping with cancer (Chen, 2005; Zane, Takeuchi, & Young, 1994). The increasing body of studies on cancer in Asian Americans strongly suggests that preventive practices and perceptions of cancer vary according to cultural beliefs, lack of knowledge, and sociolinguistic barriers. To date, most of the literature related to cancer in Chinese Americans has focused primarily on cancer prevention and screening in healthy Asian populations. Studies investigating cancer symptom experiences in Chinese patients have been conducted mostly in other countries in the Asia-Pacific region. Few studies have explored issues of cancer control, self-management, coping with cancer, and survivorship in Chinese American patients. Studies that propose to examine cancer symptom management and self-care of Chinese American patients with cancer foster an understanding of cancer care as perceived by that community.

The present study was conducted to explore the symptom experience, self-care strategies, and QOL of Chinese-speaking cancer immigrants and Chinese Americans during outpatient chemotherapy, and the feasibility of translating existing questionnaires. The purpose of the study was to establish the groundwork to provide culturally responsive information and implement healthcare programs that assist individuals to manage active treatment for cancer. Furthermore, if deficits in knowledge and self-care activities are documented, future research can target interventions.

Study Framework

The study framework is based on the University of California, San Francisco Symptom Management Model (Dodd, Janson, et al., 2001). In the model, dimensions of symptom management are conceptualized, including symptom experience, symptom management strategies, and outcomes. The symptom experience includes patients' perceptions of symptoms, evaluations of symptoms, and responses to symptoms. The symptom management strategy dimension includes the specifics of the intervention (i.e., what, when, why, where, how much, and to whom). Examples of the outcome dimension include functional status, emotional status, self-care, costs, QOL, morbidity and comorbidity, and mortality. The model also places the experience of symptom management in the context of the domains of person, health and illness, and environment.

In the present study, the symptom experience, which is the first dimension of the model, includes the frequency, severity, distress, and duration of side effects and symptoms that Chinese patients experienced during chemotherapy. Symptom management strategies focus on the use and effectiveness of self-care symptom management strategies (performed by patients themselves) in the study. The symptom outcome is the QOL experienced during the treatment period. The person domain includes demographic variables. The environment domain includes the variable of acculturation level and cultural aspects related to Chinese culture. Acculturation refers to the

interaction and modification of attitudes, values, or behaviors of a group or individual as a result of interaction with a different culture (Berry, 1986; Suinn, Rickard-Figueroa, Lew, & Vigil, 1987). The health and illness domain refers to cancer diagnosis and stage and chemotherapy for cancer. The study model is depicted in Figure 1.

Methods

The study was planned as an exploratory study that employed a descriptive follow-up method to examine symptoms, self-care, and QOL that were self-reported by Chinese American and immigrant patients with cancer.

Sample and Setting

Chinese patients who were receiving chemotherapy were actively recruited at an outpatient infusion unit of a metropolitan county hospital in northern California from September 2003 to October 2004. The county hospital serves a multicultural and lower socioeconomic community. Patients who were self-identified as Chinese, able to read and speak Chinese or English, older than 21 years, and receiving a second or third cycle of chemotherapy were recruited through flyers written in Chinese at the clinic and referral from healthcare providers. When potential participants agreed to participate, bilingual (able to speak Cantonese and Mandarin dialects) research assistants explained the study purpose, consent form, and study procedure to patients. Consent forms were provided in English and Chinese. The study protocol was reviewed and approved by the institutional review board of the University of California, San Francisco.

Forty-three eligible Chinese patients were identified as potential participants at the setting during the data collection period. Among them, nine refused to participate and six were missed because of a change of treatment protocol or no-show for appointment. Reasons for refusing to participate included: do not want to talk about cancer, do not want to be bothered, too busy, family does not want the patient to participate, and concern for privacy. Twenty-five participants agreed to be in the study.

Instruments

Study questionnaires included a basic demographic data form, the Suinn-Lew Asian Self-Identity Acculturation

Scale (SL-ASIA), the Memorial Symptom Assessment Scale (MSAS), the Self-Care Diary (SCD), the Multidimensional Quality of Life Scale–Cancer (MQOLS–CA), the Short Form 36 Health Survey ([SF-36[®]], Quality Metric, Inc.), and a brief medical information form to abstract disease information from the medical record.

The **SL-ASIA** consists of 26 multiple-choice items that assess acculturation based on language, identity, friendship choice, behaviors, generational and geographic history, attitudes, beliefs, and self-descriptions. The first 21 items measure acculturation, ranging from 1 = low acculturation (i.e., high Asian identity) to 5 = high acculturation (i.e., high Western identity or high assimilation). The instrument has established validity and internal consistency reliability coefficient of 0.88 in a sample of healthy Asian college students (Suinn, 1998; Suinn, Ahuna, & Khoo, 1992; Suinn et al., 1987). The word “Chinese” was added to items for targeted participants.

The **MSAS** measures 32 physical and psychological symptoms using the dimensions of frequency, severity, and distress. An average total symptom score can be calculated based on the scale. The instrument was tested in patients with cancer with adequate reliability in subscales (Cronbach’s alpha coefficients = 0.83 and 0.88). The construct validity of the scale also was tested with a number of measures, including the Symptom Distress Scale, the Rand Mental Health Inventory, the Functional Living Index–Cancer, and the Karnofsky Performance Scale (Portenoy et al., 1994).

The **SCD** measures the use and effectiveness of self-care activities that are used to manage symptoms and side effects of chemotherapy. The scale includes a list of self-care activities for 16 symptoms and a six-point scale to rate the effectiveness of the activities in the past three days. Additional space is provided to list self-care activities not included in the instrument. The number of self-care activities and their efficacy can be summed and averaged. The scale had established validity and test-retest reliability coefficient of 0.80 and test-retest reliability of 0.33 in a sample of Caucasian women diagnosed with breast cancer (Nail et al., 1991).

The **MQOLS-CA** is a 33-item cancer-specific QOL measure, with each item scored on a numeric rating scale from 0–10. The total average score indicates the level of QOL perceived by patients with cancer (Padilla et al., 1983; Padilla, Grant, Ferrell, & Presant, 1996). The alpha reliability of 0.91 was reported (Dodd, Dibble, et al., 2001)

The **SF-36** is a generic QOL instrument with 36 items in eight subscales (physical function, role limitations caused by physical problems, role limitations caused by emotional problems, social function, emotional well-being, energy and fatigue, pain, and general health perceptions) (Ren et al., 1998). The validity and reliability of the scale have been well established in a variety of chronically ill patients. The evaluation of the Chinese version of the SF-36 was reported in the International QOL Assessment Project.

The existing Chinese versions of the SF-36 (Ren et al., 1998) and the SL-ASIA (Suinn, 1998) were used with permission. Because no Chinese versions were available for the MSAS, SCD, or MQOLS-CA, they were translated into written Chinese using backward and forward translation (Varricchio, 1997). The traditional Chinese character system was used in the written Chinese version questionnaires because it is used more widely in current newspapers and magazines available in the Chinese American community and can be read and understood by Chi-

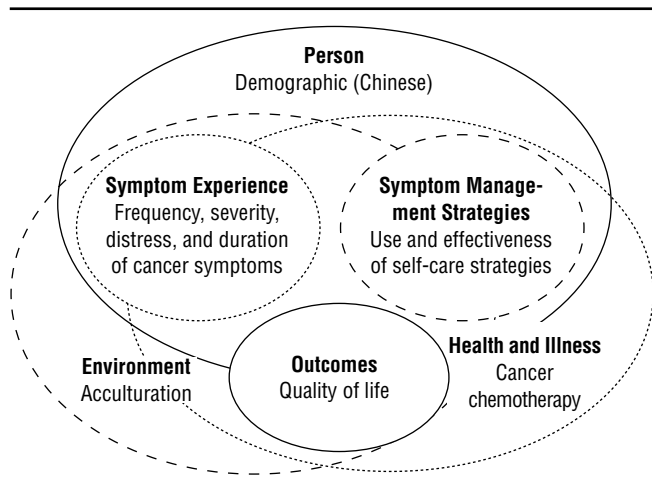


Figure 1. Study Model

nese people originally from other regions in Asia (e.g., Taiwan, Hong Kong, Singapore) and older Chinese immigrants.

NJStar Communicator 2.30, developed for typing Chinese characters in an English version of Microsoft® Windows® (Microsoft Corporation) was used for typing the translated instruments. Two bilingual people with expertise in translation of healthcare-related documents independently translated the instruments, one from the version with the target language back to the source language and the other vice versa. Items were compared until agreement was reached.

Before study enrollment, 10 volunteer Chinese-speaking patients with cancer were asked to review the translated Chinese-version instruments. Nine of the 10 were able to comprehend and had no difficulty in understanding regardless of their preference for Mandarin or Cantonese dialect.

Procedure

After participants gave their consent, they received three weekly questionnaire booklets to complete for their self-reported weekly symptom experience, weekly self-care activities, and QOL during one chemotherapy cycle. Each questionnaire booklet included Chinese and English versions of questionnaires. Participants could choose either version to complete. The bilingual research assistants who were able to speak Mandarin and Cantonese provided weekly telephone follow-ups. Completed questionnaires were returned by mail in prepaid envelopes or in person to the investigator. All data were entered into SPSS® (SPSS Inc.). Descriptive statistics were used for sample characteristics, number of symptoms experienced, symptom scores, use of self-care strategies, and QOL scores.

Results

Twenty-five patients participated in the study. The mean age of the sample was 52.36 years (SD = 8.12) and 60% were male. The cancer diagnoses included lung (24%), nasopharyngeal (24%), gastrointestinal tract (20%), ovarian and uterine (16%), breast (12%), and other (4%). Forty-four percent of the participants spoke little English and 88% could not read English. All of the subjects selected the Chinese version of the questionnaires. All participants were first-generation immigrants with low to moderate levels of acculturation (\bar{X} = 1.45, SD = 0.38). The length of time living in the United States ranged from less than one year to 36 years. Sixty-four percent of the participants had a household annual income of less than \$20,000. All of the participants lived in the city of San Francisco. Fifty-six percent of the participants reported that they were able to speak Mandarin and Cantonese dialects (see Table 1).

On average, participants experienced 14 symptoms during chemotherapy. Average MSAS scores were 1.55 (SD = 0.73) in week 1, 2.10 (SD = 0.38) in week 2, and 2.09 (SD = 0.52) in week 3. Symptoms reported most frequently included lack of energy, hair loss, dry mouth, nausea, feeling sad, sleep difficulty, mouth sores, and loss of appetite. The prevalence of the 10 most frequently reported symptoms are summarized in Table 2. On weekly SCDs, participants reported using 16–21 self-care activities. About two to three self-care strategies were reported by participants to manage each reported symptom on the SCD questionnaire. Low to moderate levels of effectiveness were reported for the selected self-care strategies (\bar{X} [SD] week 1 = 2.21 [1.16]; \bar{X} [SD] week 2 = 1.43

Table 1. Sample Characteristics

Characteristic	\bar{X}	Range	SD
Age (years)	52.36	31–71	8.12
Years living in the United States	13.54	0.08–36	10.23
Characteristic	n	%	
Gender			
Male	15	60	
Female	10	40	
Lives alone	4	16	
High school education and above	19	76	
Does not work for pay	24	96	
Household income less than \$20,000	16	64	
No health insurance	13	52	
Birth place			
China	22	88	
Hong Kong	3	12	
Dialect			
Cantonese	9	36	
Mandarin	2	8	
Mandarin and Cantonese	14	56	
Able to speak little or some English	11	44	
Able to read little or some English	3	12	
Able to read Chinese well	25	100	

N = 25

[0.97]; \bar{X} [SD] week 3 = 1.94 [1.10]). Twenty percent of the participants reported that they had used some form of Chinese herbal medicine concurrently with their chemotherapy.

Overall, participants reported low to moderate QOL. The mean score of MQOLS-CA was 5.53 (SD = 1.15) in week 1 and 5.45 (SD = 1.15) in week 3. Low scores were reported on the SF-36 subscales of role-physical, general health, vitality, and role-emotional (see Figure 2). Paired two-tailed t tests showed no significant differences between week 1 and week 3 assessments on the MQOLS-CA and SF-36.

Discussion

In general, the results from the study suggest that participants experienced multiple symptoms during chemotherapy; however, few self-care strategies were reported to be used. The finding is consistent with previous studies (Dodd, 1983, 1988; Nail et al., 1991) that reported on patients who experienced several symptoms during chemotherapy but used few self-care activities. The low report of self-care activities from the questionnaires in the present study could suggest the possible need for more patient education on self-management and self-care practice for Chinese patients. On the other hand, strategies that were listed on the questionnaire may not have included participants' usual activities. Future research can incorporate open-ended questions or qualitative data collection to solicit more information from participants.

QOL reported in the study was lower in comparison to other studies that used the MQOLS-CA (Dodd, Dibble, et al., 2001) and the Chinese version of the SF-36 (Ren et al., 1998; Yu, Coons, Draugalis, Ren, & Hays, 2003), particularly on the subscales of role-physical, general health, vitality, and role-emotional. The low SF-36 subscale scores may be a result of participants associating frequently reported

Table 2. Weekly Prevalence of Top 10 Symptoms Participants Experienced While Receiving Chemotherapy

Symptom	n	%
Week 1		
Lack of energy	19	76
Dry mouth	19	76
Hair loss	19	76
Nausea	16	64
Lack of appetite	15	60
Pain	14	56
Difficulty sleeping	14	56
Feeling sad	14	56
Constipation	14	56
Feeling drowsy	13	52
Week 2		
Lack of energy	17	68
Difficulty sleeping	17	68
Lack of appetite	17	68
Mouth sores	15	60
Pain	15	60
Feeling sad	15	60
Nausea	15	60
Dry mouth	15	60
Hair loss	15	60
Feeling drowsy	14	56
Week 3		
Lack of energy	16	64
Hair loss	16	64
Feeling sad	15	60
Dry mouth	15	60
Difficulty sleeping	13	52
Constipation	13	52
Lack of appetite	13	52
Dizziness	12	48
Numbness or tingling in the hands or feet	12	48
Worrying	12	48

N = 25

symptoms, such as lack of energy and feeling sad, with those subscales. Future studies could include larger samples and target prevalent symptoms and QOL in Chinese and Asian communities.

Twenty percent of participants reported using Chinese herbal medicine. Several survey studies have documented the common use of complementary and alternative medicine (CAM) across ethnic groups in general clinical populations (Hsiao et al., 2006; Kronenberg, Cushman, Wade, Kalmuss, & Chao, 2006; Mackenzie, Taylor, Bloom, Hufford, & Johnson, 2003; Najm, Reinsch, Hoehler, & Tobis, 2003). As for patients with cancer across ethnic groups, the prevalence of using at least one form of CAM was 40%–80% (Chan et al., 2005; Nahleh & Tabbara, 2003). On a survey of the Chinese community at the Chinatown health fairs of San Francisco and Oakland in California, about 82% of 205 respondents reported using at least one type of herbal product (Cheng, Lee, Li, Dennehy, & Tsourounis, 2004). Given those prevalent survey studies, perhaps the use of Chinese medicine from present study participants was underreported. Some participants may not have disclosed the information fully when they completed the questionnaires. As suggested from a survey in Chinese and Vietnamese American communities by Ahn et al. (2006), although about 70% of respondents reported that

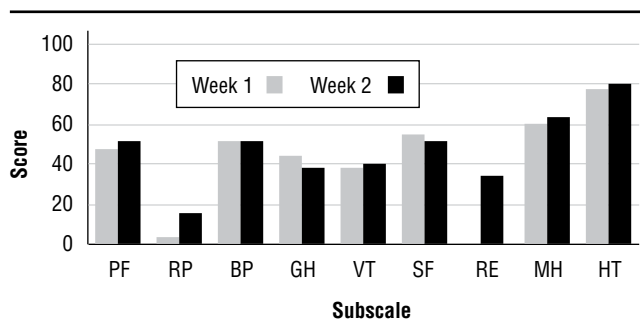
they used some form of CAM, only 8% had discussed their use of CAM with healthcare providers. Some participants may have been hesitant to disclose their use of CAM because data were collected primarily in a hospital where their healthcare providers were often present. Future studies could include community-based recruitment and add more questions regarding specific CAM use.

Limitations

Although the study contributes to the limited knowledge of cancer symptom management in Chinese Americans, it has some limitations. Concomitant use of open-ended questions or interview questions that assess self-care strategies might be able to capture additional strategies that could include more specific information on complementary treatments. Another limitation was the small sample size recruited in one clinical setting. Continued investigation in a less homogeneous sample will provide a better understanding of self-care in Chinese American communities.

Research and Clinical Implications

The study has implications for further research on instrument validation and development regarding symptom experience and outreach recruitment of patients with cancer with socioeconomic and language barriers. Most data collection strategies that were employed, such as bilingual staff members and translated questionnaires and study documents, were shown to be culturally appropriate. However, the stigma regarding cancer could be one of the challenges related to subject recruitment and data collection in the Chinese community. As noted during the study, several participants expressed privacy concerns during study recruitment and follow-up contacts, such as wanting to ensure that their neighbors would not know they had cancer. In some parts of Chinese communities in the United States, cancer still is stigmatized as a contagious disease or a condition caused by immoral behaviors (Wong-Kim, Sun, & Demattos, 2003). Because the sample pool of the study was limited to one clinical setting in the city of San Francisco, further studies with multiple settings and various Chinese communities are necessary for exploring the perception of cancer among ethnically diverse patients with cancer and cancer's effect on patient-provider relationships and long-term cancer management.



BP—bodily pain; GH—general health; HT—health transition; MH—mental health; PF—physical functioning; RE—role-emotional; RP—role-physical; SF—social functioning; VT—vitality

Figure 2. Short Form 36 Health Survey Results

The study has clinical implications for culturally sensitive cancer care. Effective patient-provider communication is a key process to maintain effective symptom management and self-management. When patients are not fluent in the language used to communicate, nurses and other healthcare providers may face challenges when trying to assess symptoms accurately and manage symptoms appropriately. To ensure an optimal level of care for patients with socioeconomic and language barriers, continued investigation is needed to develop

innovative and effective interventions for cancer symptom assessment and patient education specifically targeted at patients with diverse cultural backgrounds.

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