Where are we and where to go for supportive cancer care in China? A national survey of patients and healthcare providers

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Abstract

This study aimed to make a comprehensive, nationwide survey of supportive care for cancer patients in China. Two sets of questionnaires, one for medical professionals and one for patients, were distributed. Responses were received from 12,686 medical care personnel and 11,172 patients or their family representatives from 34 provinces. It was found that only about one-fourth of caregivers felt they had much knowledge about oncology supportive care, and nearly 10% admitted to having little or no knowledge. Multidisciplinary teams for supportive care were more often available in tertiary hospitals (19.9%) than in non-tertiary hospitals (15.4%) (p < 0.05). Pain was the most common patient concern; however, pain treatment was only the fifth most common therapy administered by health care providers. Patient concerns were more often subjective (pain, economic burden, appearance, and sexual dysfunction), whereas caregiver treatments were more often directed at objective concerns (nutrition and adverse reactions to treatment regimens). Patients reported that they received no guidance or guidance only when they proposed it for psychological (25%), physical exercise (15%), nutrition (40%), or spiritual (40%-65%) needs. We conclude that the concept of supportive care is widely accepted and implemented throughout China. However, gaps exist in caregiver knowledge about supportive oncology care, the use of multidisciplinary teams, especially in non-tertiary hospitals, and the interventions between what caregivers give and what patients subjectively need. Improvements in caregiver education in supportive oncology care and the delivery of care are needed.

1. Introduction

Cancer is the leading cause of death worldwide, and the incidence in China has been rising rapidly; nearly 24% (4.3 million) of cases and 30% (2.9 million) of deaths from cancer in 2018 occurred in China. In addition to medical issues, cancer patients are affected by reduced quality of life and psychosocial, family, financial, and work-related issues. They need support throughout their entire journey with the illness.

Cancer supportive care is an umbrella term for all services that patients may require throughout their cancer experience. Rehabilitation, secondary cancer prevention, survivorship, and end-of-life care are integral to supportive care. Temel et al. have stated that early palliative therapies can significantly improve the quality of life, reduce severe depressive symptoms, and prolong survival times of patients with metastatic lung cancer.

Compared with developed regions of the world, supportive cancer care in the Asia-Pacific region faces more challenges and is far from meeting the needs of patients, and much research in the area has not been carried out well. Moreover, many professionals and patients do not know the similarities and differences between supportive cancer care and palliative therapy. Palliative therapy is a category of supportive cancer care, whereas cancer support care emphasizes the entire process from the diagnosis to the end of life. The World Hospice Palliative Care Alliance has reported the unmet need for cancer supportive care in resource limited countries. Despite these problems, progress is being made in the field
of supportive cancer care in China, especially for women with advanced breast cancer, through the Supportive Care Needs Survey. 3,6-9

This study was initiated and implemented by the Committee of Neoplastic Supportive Care of the Chinese Anti-Cancer Association. The study was based on two sets of questionnaires that were jointly designed by clinical oncologists and statisticians for medical professionals and cancer patients. The content of The questionnaires covered the concepts of supportive cancer care, treatment of cancer-related complications, treatment-associated problems, pain management, nutritional support, psychological intervention, physical exercise intervention, family economics, and alternative therapies. The questionnaires were intended to reveal the general awareness and practice of supportive cancer care nationwide, find defects in practice and the unmet needs of patients, and provide the basis for better clinical practice guidance and clinical research in the field in China.

2. Methods

2.1. Questionnaires

The questionnaires were distributed by clinical oncologists and statisticians. The questionnaire for medical care personnel included questions on basic information, cognition of supportive care for cancer, practical conditions of supportive care, and views on the prospects of supportive care in China. The questionnaire for the patients or family members included questions on the patient’s basic information and their experience with various aspects of the therapeutic regimen, such as cancer pain, nutrition, psychological state, physical exercises, religious counseling, and Chinese traditional medicine. The questionnaires were posted and recovered by a third-party internet research platform (https://www.wjx.cn/).

2.2 Ethics approval

This work was deemed not requiring approval by the China Association for Ethical Studies. Local approval was gained from research and development departments at the participating centers. All participants were given full information about the project, and their consent was indicated by the completion and return of the questionnaires. All questionnaires were anonymous.

2.3 Data analysis and statistics

Data were analyzed by the Statistical Package for the Social Sciences version 22.0 (SPSS Inc., Chicago, IL). A Chi-square test was used to compare numerical data. A non-parametric test was used for comparison of ordered classification variables. The average composite score for multiple options was calculated as (∑ frequency × weight)/number of times this question was filled in), and the weight was determined by where the options were ranked. A difference with p < 0.05 was considered statistically significant.
3. Results

3.1. General information and demographics

Responses to the questionnaire were received from 12,686 medical care personnel and 11,172 patients or their families from 34 provinces throughout the country. The map in Supplementary Figure 1 illustrates that the geographic distribution of these two data sources was similar, reflecting the overall population distribution and epidemiology of cancer in China, i.e., denser in the east than in the west.

3.1.1. Caregiver demographics. Table 1A.

About 71% of caregivers were female. The most common age range was 31-40 years (39.8%); about 82% were employed in tertiary hospitals. About 90% felt they had much or moderate knowledge of supportive oncology, and about 95% felt that their organization placed much or moderate emphasis on supportive care.

3.1.2 Patient demographic. Table 1B.

About 40% of questionnaires were completed by the patients, 60% by family members. Forty-seven percent of respondents were male, and about 78% were older than 31 years. The most common tumor types were breast, colon/rectum/anus, respiratory tract, and stomach. About 75% of patients had education beyond primary school, and 88% were cared for in tertiary hospitals.

3.2 Cognition of illness

Figure 1 presents patients’ awareness of their disease according to age and educational background. The overall disease awareness rate was 77.0%. Adult patients (age 21-60) had a higher rate of awareness of the disease than did juveniles (<20 years) and elderly patients (>60 years) \( p < 0.05 \). Patients with a college/bachelor degree had a higher rate of awareness than did those with a higher or lower degree \( p < 0.05 \).

3.3 Practice modes of supportive cancer care in Chinese hospitals

Figure 2 illustrates the primary supportive practices of cancer care in China. These include regular consultation with a multidisciplinary team (MDT), available consultation from related departments, and decisions made by the attending physician in charge that are never or seldom carried out. The proportion of regular MDTs and available consultation from related departments was higher in tertiary hospitals (19.9%) than in non-tertiary hospitals (15.4%) \( p < 0.05 \), although MDT was available in only a minority of the hospitals.

3.4 Clinical features of patients

Patients’ clinical features (pain, nutrition, psychology, and exercise) are presented in Supplemental Table 1.
3.4.1 Pain

Cancer pain was present in 42.6% of patients, but over half of them (54.7%) endured the pain rather than asking for pain-relief medications. Of those who received analgesics, 53.3% received oral preparations, 14.1% received patches, and 22.9% received injections.

Most (72.0%) of health care providers indicated that they followed the World Health Organization algorithm for cancer pain management, which aims to achieve a target state of “painless sleep, painless rest, and painless activities.” Among the providers, 13.9% gave patients strong opioids orally, and only as needed, 6.1% routinely administered analgesics by patch or subcutaneous injection to reduce oral drug toxicity, and 8.0% treated only severe and persistent pain or severe outbursts of pain.

In about 66% of patients, the expected goal of analgesia was achieved, i.e., 21.4% of patients experienced little or no pain after treatment; 44.6% experienced pain at times, but it did not affect their sleep, rest, or general daily activities; and 34.0% experienced poor analgesic effects, and pain affected their daily lives.

We compared the response to analgesia given on-demand to the response given on schedule (Figure 3). For severe pain (life-affected pain), 41.4% of patients got relief with on-demand analgesia compared with 32.3% who got relief with on-schedule analgesia. For moderately severe pain (life-unaffected pain), 40.9% of patients got relief of pain with on-demand analgesia vs. 47.0% with on-schedule analgesia. Figure 4 also illustrates that the degree of pain relief achieved did not differ between patients treated at tertiary and other hospitals (p > 0.05).

3.4.2 Nutrition

Nutritional care was the third most common supportive treatment for tumor patients. Medical care personnel reported a high rate (76%) of involvement in patients’ nutrition care during the patients’ entire course and 23% during part of the course. Sixty-six percent of personnel reported screening routinely to identify patients at high risk of malnutrition, 21% reported giving nutritional therapies when patients presented with need for nutritional support but with no symptoms of malnutrition, and 13% took action only after patients had malnutrition. Patients reported somewhat less involvement of personnel in their nutrition (about 10% reported no guidance; about 29% reported guidance when the patient proposed, and about 62% reported caregiver-initiated guidance) (Supplemental Table 1). About 45% of patients eventually received supplemental nutritional care (52% with oral nutrients or fluids, 39% with intravenous infusion, and 9% by nasal tube feeding of gastric/jejunostomy fistula). The rate of nutrition treatment in tertiary hospitals was significantly lower than in primary and secondary hospitals (42.3% versus 64.9%, p < 0.05, Figure 4).

3.4.3 Psychology

The cancer patients commonly reported psychological problems, about 71% with varying degrees of anxiety; 49% with varying degrees of depression; and 55% with varying degrees of despair. The main
causes of psychological stress were concern about control of disease (71%), financial stress (45%), and pain control (22%). About 95% of physicians considered patients’ financial situation in the development of treatment plans. About 75% of patients reported that medical staff took the initiative in providing psychological guidance. No significant difference in the psychological counseling provision between tertiary and non-tertiary hospitals was found (Figure 4).

3.4.4 Exercise

About two-thirds of health-care providers reported exercise intervention over the entire disease course, whereas about 8% reported that they were never concerned about this aspect of care. About 84% of patients reported receiving advice on physical exercise, and low-intensity exercise was available to most patients (70%). However, only about 18% of patients exercised at the moderate intensity recommended by the guidelines; 11% about 5% exercised at high intensity, and 8% never exercised. There was no significant difference in physical intervention between tertiary and non-tertiary hospitals (Figure 4).

3.4.5 Traditional Chinese medicines and religious counseling

Sixty-four percent of patients had an interest in or had tried traditional Chinese medicine (TCM), and 42% had tried to find religious counseling. A lower percentage (30%) of health care providers would support patients using TCM, and 20% would heed the patients’ religious needs. Around 20% of patients thought TCM or religious counseling was effective.

3.4.6 The most common patient complaints and the care received

We compared the patients’ most common complaints with the most frequent treatments administered by caregivers (Table 2). Much discordance was recorded. Of the 10 most common complaints, pain was the primary concern. However, pain treatments did not even rank in the top 10 treatment measures that caregivers provided. Subjective concerns, such as changes in appearance, economic burden, fatigue, and sexual dysfunction were also among the top 10 patient concerns, whereas the care administered was more often directed at toxicities and adverse reactions to chemotherapeutic and radiation therapy.

4. Discussion

This study, initiated and implemented by the Committee of Neoplastic Supportive-care of Chinese Anti-Cancer Association, aimed to examine the awareness and practice of supportive cancer care throughout China. It also aimed to find defects in practice and the unmet needs of patients and provide the basis for improved clinical guidance and research in the primary care practices of China. A rationale for conducting the study was that, compared with developed regions worldwide, supportive cancer care in the Asia-Pacific region faces more challenges and is felt to fall short of meeting patient needs. A step towards changing the status quo was to assess the supportive care of Chinese cancer patients. This was accomplished by distributing and analyzing the responses to questionnaires given to cancer caregivers and patients or family members throughout China.
The questionnaires were jointly designed by clinical oncologists and statisticians and were divided into a medical caregiver version and a patient/family member version. The accumulated data represented 34 provincial administrative regions of the country, with 12,686 medical staff and 11,172 patients (or their families) participating. The geographic distribution of the respondents suggested that some level of supportive care was available to cancer patients throughout the nation, including the least populated, non-urban areas. Moreover, the sample size of both the medical staff and patients was large, thus reducing the chance for selective, regional biases.

An important and probably reassuring finding of the survey was that more than two-thirds of health care providers felt that their organizations placed much or moderate emphasis on supportive care. On the other hand, only about one-fourth of caregivers felt they knew much about oncology supportive care, and nearly 10% admitted to having had little or knowledge of this kind of care. These figures may indicate that more education or training of caregivers in supportive care is needed in China – even in tertiary hospitals, as over 80% of the surveyed caregivers were working in tertiary hospitals.

In this study, both medical care personnel and the patients or family proxies suggested that about one-third of the patients were ignorant of their illness. The awareness rate of adolescents (< 20 years old) and elderly patients (> 60 years old) was lower than that of middle-aged patients. Perhaps teenagers and the elderly are in a relatively weak position in the family, and the family tends to protect them from a knowledge of their illnesses. The awareness rate of patients with low educational backgrounds (primary school and below) and high educational backgrounds (master’s degree and above) were lower than those with medium educational backgrounds. Unexpectedly, though, the knowledge rate of people with the highest educational backgrounds (master’s degree or above) was lower than that of people with medium educational backgrounds; this finding is unexplained and could simply be the result of a relatively small sample.

The rate of patient awareness of cancer illness and the severity of cancer diagnoses in China and other Asian countries is lower than in Western countries, no doubt because of cultural differences. Eastern countries are deeply influenced by Confucianism in their moral traditions, with emphasis on morality and obligation, and the rights of families and collectives to make decisions for patients. Whether an increase in patient awareness of their cancer diagnosis should be an objective of supportive care in China is a question beyond the scope of this investigation but is worth investigation.

The survey also revealed a modestly but significantly higher rate of MDT consultation for supportive care in tertiary care hospitals than in non-tertiary care hospitals in China (about 20% vs. 15%). This difference suggests that tertiary hospitals have a more comprehensive and better-equipped model of supportive cancer care than do primary hospitals, which have a simpler model, with the attending physician developing all treatment plans. Irrespective of the differences, only a minority of hospitals, either tertiary or non-tertiary hospitals have MDT supportive cancer care. Whether the MDT model of care is superior to other models and should be implemented more often in China are questions that deserve inquiry.
Pain is one of the most common and feared cancer symptoms. In this survey, nearly one-half of patients experienced cancer pain, and pain was one of the top 10 concerns of these patients regarding their disease. On the other hand, pain treatment ranked fifth among the most frequently administered medical care measures among caregivers, which might imply inadequate monitoring of cancer pain; however, many other factors might account for the difference. Although about one-half of patients tolerated pain without medication, about one-third reported that pain affected their rest and daily activities. Thus, there appears to be room for improvement in the management of cancer patient pain in hospitalized patients. Nonetheless, around 75% of caregivers indicated that they follow the World Health Organization guidelines for pain management. A higher proportion of patients in tertiary hospitals received on-demand therapy than did patients in non-tertiary hospitals. This difference is unexplained, but might reflect a greater flexibility of tertiary hospitals to adjust pain medication protocols to a patient's needs (perhaps through a higher level of staffing). Overall, though, the effectiveness of pain management was reported similar in tertiary and non-tertiary hospitals.

Nutritional support is a major requirement for many cancer patients, who often experience nausea, vomiting, and anorexia, and have increased catabolism. In this survey, caregivers reported a nearly 100% rate of involvement in patient nutrition, either throughout the entire course or during part of the course, and over 60% reported screening to identify patients at high risk of malnutrition. On the other hand, patients reported that caregivers were less involved in their nutritional needs; about 40% reported no guidance or guidance only when they proposed it. This difference is unexplained but might indicate patient ignorance in how involved a caregiver is in supplying their nutritional needs. About 45% of patients eventually received supplemental nutritional support, with about half of them needed parenteral, nasal tube, or gastric/jejunostomy fistula nutritional support.

Physical rehabilitation guidance has played a role in supportive care during and after cancer treatment. Knols et al. found that the experimental group had significantly improved function, mental health status, and nausea during breast cancer therapy. Cramp et al. reported that completing exercise plans significantly improved cancer-related fatigue. Some recommended that tumor survivors follow the exercise guidelines issued by the International Multidisciplinary Roundtable, which include graded levels of exercise. In our study, about 80% of patients received guidance on physical activity, but about 70% performed only low-intensity exercises, which did not meet the standard exercise guidelines.

As expected, a high percentage of the cancer patients in this survey experienced emotional challenges. About 50%-70% noted various degrees of anxiety, depression, and despair. Most mental stress came from feeling a lack of control over their disease and the economic burden of treatments. Psychological counseling was reported to be available for about 75% of patients, with no difference in availability between tertiary and non-tertiary hospitals; thus, about 25% of patients felt the medical staff did not provide psychological guidance. About 95% of physicians considered a patient's financial situation in the development of treatment plans, but there was no indication of assistance for patients with a financial hardship.
In this survey, the percentage of patients who expressed interest in using TCM or seeking religious counseling was substantially higher than the percentage of health care providers who said they would support these desires. This disparity might highlight a need for the providers to be more sensitive to patient spiritual and emotional needs. Patient interest in using TCMs is likely evidence that traditional treatments occupy an important position in the emotions of Chinese cancer patients, and they are not just a "placebo."\textsuperscript{16}

We were interested in how the patients’ concerns corresponded with the therapeutic measures that caregivers administered. We found that patients were more concerned with subjective issues such as nausea, changes in appearance, economic burdens, and sexual dysfunction, whereas health care workers were more concerned with conditions that had objective indicators, such as blood toxicity, hepatic and renal toxicity, and adverse effects of therapies. At the least, these findings indicate the need for caregivers to be vigilant about patients’ perceived needs as well as the “medical” issues.

We acknowledge that this study has limitations: 1) The medical care version and the patient version of the questionnaire were designed and distributed one after the other, rather than concurrently. 2) The topics of the questionnaires were not completely matched. 3) Many issues in the vast field of supportive cancer care could not be addressed because of manpower and budget restrictions. Questionnaires in future studies should better match caregivers’ perceptions of care given and patients’ perceived needs to more accurately determine whether needs are met and, if not, where corrections are needed. The questionnaires could also evaluate, in more detail, the possible differences among levels of hospitals in providing supportive care.

Despite its limitations, this large-scale study has substantially increased knowledge of supportive cancer care in China. It compared the perceived needs of patients with the care administered by health care personnel. The study revealed that a certain level of care is available broadly throughout the nation while also revealing areas in which care might be more thoroughly evaluated or even improved. Some of these areas are 1) greater effort in education and training of oncology-patient caregivers in supportive care; 2) more comprehensive assessment of supportive care in non-tertiary care hospitals, including the possible advantages of the MDT model of care; 3) methods for improving patients’ pain control, including the use of on-demand vs. structured delivery of pain medications; 4) greater attention to patient subjective needs, including physical exercise, psychological guidance, financial burdens, and spiritual and religious support. Joint efforts of professionals, patients/families, and institutional structures will be needed to address these needs.

5. Conclusions

The concept of supportive oncology care is widely accepted and implemented throughout China, but gaps exist in the knowledge of caregivers in this aspect of care; the use of multidisciplinary teams, especially in non-tertiary hospitals; and between the interventions caregivers give and patients’ subjective needs. Improvements in caregiver education in supportive oncology care and the delivery of care are
needed. Improved organizational structures of supportive care teams, enhanced professional knowledge, and integration of medical-care personnel management likely will be needed to establish a more effective model of supportive care for the cancer patients of China.

**Declarations**

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**Competing interests**

The authors declare that they have no competing interests.

**Availability of data and materials**

All data generated or analyzed during this study are included in this paper.

**Code availability**

Not applicable

**Author contributions**

The authors acknowledge the contribution by all the CONS members, patients and their family members participated in this survey.

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**Ethics approval**

This work was deemed not requiring approval by the China Association for Ethical Studies. Local approvals were gained from research and development departments at the participating centers.

**Consent to participate**

All participants were given full information about the project, and their consent was indicated by the completion and return of the questionnaires. All questionnaires were anonymous.

**Consent for publication**

Not applicable
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Tables

Table 1. General information of healthcare providers and patients.
A. Healthcare providers  n=12,686

|                | N    | %   |
|----------------|------|-----|
| **Sex**        |      |     |
| Male           | 3735 | 29.4%|
| Female         | 8951 | 70.6%|
| **Professional position** |  |     |
| Physician      | 7117 | 56.1%|
| Nurse          | 5569 | 43.9%|
| **Level of medical institution** |  |     |
| Tertiary hospital | 10366 | 81.7%|
| Other          | 2320 | 18.3%|
| **Knowledge of Supportive Oncology** |  |     |
| Much           | 3419 | 27.0%|
| Moderate       | 8062 | 63.6%|
| Little or none | 1205 | 9.4% |
| **Importance organization places on supportive oncology** |  |     |
| Much           | 4597 | 36.6%|
| Moderate       | 7285 | 58.0%|
| Little or none | 624  | 5.4% |

B. Patients n=11,172

|                | N    | %   |
|----------------|------|-----|
| **Sex**        |      |     |
| Male           | 5242 | 46.9%|
| Female         | 5930 | 53.1%|
| **Age (year)** |      |     |
| <20            | 243  | 2.2% |
| 21-30          | 794  | 7.1% |
| 31-40          | 1241 | 11.1%|
| 41-50          | 2312 | 20.7%|
| Age       | Count | Percentage |
|-----------|-------|------------|
| 51-60     | 2891  | 25.9%      |
| >60       | 3691  | 33.0%      |

**Education background**

| Education Level             | Count | Percentage |
|-----------------------------|-------|------------|
| Elementary School           | 2712  | 24.3%      |
| Middle-High School          | 5197  | 46.5%      |
| College or Bachelor         | 2883  | 25.8%      |
| Master or Doctor            | 380   | 3.4%       |

**Tumor type**

| Tumor Type                   | Count | Percentage |
|------------------------------|-------|------------|
| Lung, trachea, bronchi       | 1833  | 16.4%      |
| Colorectum, anus             | 1778  | 15.9%      |
| Breast                       | 1694  | 15.2%      |
| Stomach                      | 1335  | 12.0%      |
| Other                        | 4060  | 40.5%      |

**Level of medical institutions**

| Level of Medical Institutions | Count | Percentage |
|-------------------------------|-------|------------|
| Tertiary hospital             | 9811  | 87.8%      |
| Other                         | 1361  | 12.2%      |

**Table 2.** Symptoms of greatest concern to oncology patients and issues most often addressed by health care providers. The average composite score = (Σ frequency × weight)/number of times this question was filled in, and the weight was determined by where the options were ranked.
| Most concerns of patients                                      | Average Composite Score |
|---------------------------------------------------------------|-------------------------|
| Pain                                                          | 7.54                    |
| Nausea, vomiting                                              | 6.25                    |
| Hematologic toxicities                                        | 3.19                    |
| Changes in appearance, e.g. baldness or skin reactions        | 3.18                    |
| Economic burden                                               | 2.95                    |
| Dysfunction of vital organs                                   | 2.45                    |
| Inconvenience of venous catheter                              | 0.64                    |
| Fatigue                                                       | 0.54                    |
| Sexual dysfunction                                            | 0.23                    |
| Other                                                         | 0.03                    |

| Most common treatments given                                  | Average Composite Score |
|---------------------------------------------------------------|-------------------------|
| Hematologic toxicities                                        | 15.11                   |
| Nausea, vomiting                                              | 14.67                   |
| Nutrition                                                     | 11.45                   |
| Diarrhea, constipation                                        | 8.54                    |
| Analgesia                                                     | 8.04                    |
| Hepatic and renal toxicity from chemotherapy                  | 5.48                    |
| Allergy                                                       | 5.40                    |
| Adverse reaction from radiotherapy                            | 5.26                    |
| Adverse reaction in oral mucosa                               | 3.05                    |
| Psychological interventions                                  | 2.03                    |

**Figures**
Figure 1

Percent of patients aware of their disease or condition according to age and educational background. *p <0.05
Figure 2

Practice patterns of supportive cancer care. The availability of regular multidisciplinary teams (MDTs) in tertiary hospitals is higher than in non-tertiary hospitals. * p < 0.05.
Figure 3

Analgesic efficacies. The vertical axis indicates the percentage of patients who reported relief of pain.

Figure 4

Nutritional treatment, physical intervention, and psychological counseling in the two hospital types. *: p < 0.05.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

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- SupplementaryTable.docx