Self-perceived Burden among Advanced Cancer Patients: A Cross-Sectional Survey

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Abstract: Objective: The aims of this study are to explore the prevalence and the influencing factors of SPB (self-perceived burden) among advanced cancer patients. Methods: One hundred fifty-six patients were recruited from the Oncology Comprehensive wards of a comprehensive hospital in Zhuhai city from January to December 2019. Data consisted of a series of questionnaires a week after the patients’ hospitalization. Relevant statistical analyses were conducted using SPSS 25.0. Results: 58.34% patients reported moderate to severe SPB (VAS ≥ 50 mm). Patients’ SPB was associated with place of residence (β=0.160, p=0.049), and time since cancer diagnosis with 7~12 months (β=-0.266, p=0.009) and moderate medical burden (β=-0.209, p=0.037) scores. The proportion of explained variance was 36.0%. Conclusion: Health care professionals should be aware that about over half of advanced cancer patients experience moderate to severe SPB. They should adapt their support of patients who report such a feeling.

Key words: self-perceived burden, advanced cancer.

1. Introduction

Malignant tumor, also known as cancer, is a kind of systemic consumptive disease with long course, high mortality and serious harm to human health. The latest statistics show that there are about 18.1 million new cancer cases and 9.6 million deaths in the world in 2018[1]. In China, in 2015 alone, the number of new cancer cases reached 4.292 million and the number of deaths reached 2.814 million[2].

Most patients with malignant tumors have suffered a great psychological impact since they were diagnosed, and patients with advanced malignant tumors mean dying and being given a death notice, and the patients are suffering physically and psychologically. As a result, some patients have adverse emotional reactions such as depression and restlessness, and even refuse treatment and underweight. This also brings great difficulties and challenges to the follow-up treatment and nursing of the disease[3]. Patients with advanced cancer frequently worry about being a burden to their families[4, 5]. Patients’ SPB (self-perceived burden) refers to “an empathic concern engendered from the impact on others of one’s illness and care needs, resulting in guilt, distress, feelings of responsibility, and diminished sense of self” [6]. SPB can easily cause depression, anxiety, self-guilt, remorse, and even express the thoughts of death and suicidal, which seriously affects the quality of life, interferes with adherence of treatment, but also makes their caregivers feel at a loss[7]. To our knowledge, SPB has rarely been studied in oncology, except in the context of palliative care. One study demonstrated that 65% of patients with advanced cancer experienced minimal SPB and 19% experienced moderate to extreme SPB[8]. Other studies have been conducted among patients with chronic pain or terminal illness to assess factors associated with SPB[9-11].
The aim of this study was to assess the prevalence and to explore the influencing factors of SPB in patients with advanced cancer. Disconsistent with recommendations of previous research, this study focused on multiple cancer types, due to the identified representativeness of patients with advanced malignant tumors, the growing population of cancer survivors and consequent priorities for health care systems.

2. Methods

This study was conducted in the Fifth Affiliated Hospital of Sun Yat-sen University and was approved by the local ethics committee. All consecutive patient volunteers fulfilling the inclusion criteria were invited to participate and provided written informed consent. Recruited patients were aged ≥18 years, and were able to speak Chinese. Patients hospitalized for palliative care, those with diagnoses of advanced cancer, and those who could not complete scheduled assessments for physical or psychological reasons were excluded. Moreover, the investigators were trained in order to standardize the way to present the study and the assessment.

3. Assessment Tools

3.1 Patients’ Socio-Demographic and Medical Characteristics

Socio-demographic characteristics included gender, age, place of residence, marital status, occupation, medical payment ways, medical burden, educational level, main caregivers, and monthly income. Medical characteristics included types of cancer, mode of treatment, number of comorbidities, duration of hospitalization for cancer treatment, time since cancer diagnosis.

3.2 The Chinese version of Self-Perceived Burden Scale (SPBS-CP)

The Chinese version of Self-Perceived Burden (SPBS-CP), a 21-item, validated measure across five domains, was used to assess the SPB of cancer patients. The SPBS-CP consists of five domains: caring burden, economic burden, family burden, psychological burden, and treatment burden. Participants respond using a 5-point Likert scale ranging from 1 (no burden) to 5 (most severe burden). The burden extends to none SPB (score<30), mild SPB (score:30–50), moderate SPB (score:50–70) and severe SPB (score≥70). The revised scale has been widely used in cancer patients in China, with good reliability and validity[12].

4. Statistical Analysis

All statistical analyses were conducted using SPSS version 25.0. We conducted descriptive analyses, presented as mean, standard deviation, median and interquartile range for quantitative variables and as frequencies and proportions for categorical variables. To assess associated factors, SPB was considered as a continuous variable. Univariate relationships between patient characteristics and SPB were evaluated using parametric tests. All tests were two tailed and alpha was set at 0.05. A multiple stepwise linear regression model was then computed to assess relationships between potential predictors and patients’ SPB. All variables with univariate p-values≤0.05 were entered into the model.

5. Results

5.1 Subjects

One hundred and fifty-six (156) patients could be admitted in day care or inpatients settings according to their diagnosis and treatments. The flow of our study procedures is graphically displayed in Fig. 1. Table 1 lists patients’ socio-demographic and medical characteristics.

5.2 Prevalence of SPB

In this study, there were 141 patients (90.38%) with varying degrees of SPB, of which 32.05% patients had mild SPB, and 58.34% patients had moderate to
severe SPB. Table 2 displays the various levels of SPB.

5.3 Factors Associated with SPB

The total score of SPB of patients with advanced cancer was statistically different in different place of residence, monthly income, and time since cancer diagnosis ($p<0.05$). Table 3 displays socio-demographic and medical characteristics associated with patients’ SPB.

Fig. 1 Flow of participants through the study.

Table 1 Characteristics of patients with advanced cancer ($n=156$).

| Items                          | $n$ (%) | Items                          | $n$ (%) |
|-------------------------------|---------|-------------------------------|---------|
| Gender                        |         | Religious belief              |         |
| Male                          | 91 (58.33) | No                                 | 134 (85.90) |
| Female                        | 65 (41.67) | Yes                               | 22 (14.10) |
| Age(year)                     |         | Medical payment ways            |         |
| 18~40                         | 18 (11.54) | Medical insurance              | 147 (94.23) |
| 41~60                         | 73 (46.79) | Personal                         | 9 (5.77) |
| >60                           | 65 (41.67) | Medical burden                  |         |
| Place of residence            |         | None                             | 11 (7.05) |
| Rural                         | 94 (60.26) | Mild                             | 281 (17.94) |
| Urban                         | 62 (39.74) | Moderate                         | 75 (48.08) |
| Marital status                |         | Severe                           | 42 (26.92) |
| No                            | 10 (6.41) | Types of tumors                 |         |
| Married                       | 146 (93.59) | Head and neck tumor             | 12 (7.69) |
| Educational level             |         | Chest tumor                      | 48 (30.77) |
| Primary                       | 52 (33.33) | Abdominal tumor                  | 76 (48.72) |
| Junior                        | 43 (27.56) | Pelvic tumor                     | 20 (12.82) |
| Senior                        | 27 (17.31) | Comorbidities                   |         |
| Secondary                     | 18 (11.54) | None                             | 102 (65.38) |
| Bachelor                      | 16 (10.26) | Yes                              | 54 (34.62) |
| Occupation                    |         | Time since diagnosis (month)    |         |
| Farmers                       | 51 (32.69) | 1-3                             | 52 (33.33) |
| Workers                       | 41 (26.28) | 4-6                             | 22 (14.10) |
| Clerk                         | 22 (14.10) | 7-12                            | 51 (32.69) |
| None                          | 27 (17.30) | >12                             | 31 (19.87) |
| Others*                       | 15 (9.62) | Duration of hospitalization(month) |         |
| Monthly income(RMB)           |         | 1-3                             | 62 (39.74) |
| <3,000                        | 81 (51.92) | 4-6                             | 41 (26.28) |
| 3,001-5,000                   | 52 (33.33) | 7-10                            | 28 (19.75) |
| >5,000                        | 23 (13.74) | >10                             | 25 (16.03) |
Self-perceived Burden among Advanced Cancer Patients: A Cross-Sectional Survey

(Continued) Table 1 Characteristics of patients with advanced cancer (n=156)

| Items                      | Items                                      | n (%)   |
|----------------------------|--------------------------------------------|---------|
| Number of children         | Therapeutic methods                        |         |
| ≤1                         | Surgery                                    | 24(15.38)|
|                           | Surgery+Chem.                              | 56(35.90)|
| 2                          | Chemo.                                    | 19(12.18)|
| 3                          | Chem.+Radiotherapy                         | 27(17.31)|
| ≥4                         | Surgery+Chem.                              | 56(35.90)|
|                           | Surgery+Chem.+Radio.                       | 18(11.54)|
| Main caregivers            |                                            |         |
| Spouse                     |                                            | 96(61.54)|
| Children                   | Others                                      | 12(7.69)|
| Parents                    |                                            | 13(8.33)|
| Others                     |                                            | 10(6.41)|

6 cases of students, 9 cases of tradesman; 4 cases of nursemaid care, 3 cases of siblings care, 2 cases of self-care, 1 cases of boyfriend care; 3 cases of surgery-chemotherapy-biotherapy, 4 cases of targeted therapy, 5 cases of surgery-Chinese traditional medicine-radiotherapy.

Table 2 Various levels of SPB (n=156)

| Grades                | SPB   | n (%) |
|-----------------------|-------|-------|
| Normal                | <30   | 15(9.61)|
| Mild                  | 30~50 | 50(32.05)|
| Moderate              | 50~70 | 54(34.62)|
| Severe                | >70   | 37(23.72)|

Table 3 Univariate analysis of SPB (n=156, \( \bar{x} \pm s \))

| Items                  | n     | Overall SPB     | \( t/F \) | \( p \) | LSD-L |
|------------------------|-------|-----------------|-----------|---------|--------|
| Gender                 |       |                 |           |         |        |
| Male                   | 91    | 53.07 ± 18.52   | -1.720    | 0.087   |        |
| Female                 | 65    | 58.46 ± 20.37   |           |         |        |
| Age(year)              |       |                 |           |         |        |
| 18~40\(^{b}\)         | 18    | 50.22 ± 19.68   | 2.572     | 0.080   |        |
| 41~60\(^{b}\)         | 73    | 58.96 ± 19.25   |           |         |        |
| >60\(^{b}\)           | 65    | 52.63 ± 19.11   |           |         |        |
| Place of residence     |       |                 |           |         |        |
| Rural                  | 94    | 51.65 ± 18.60   | -2.972    | 0.003   |        |
| Urban                  | 62    | 60.87 ± 19.49   |           |         |        |
| Monthly income(RMB)    |       |                 |           |         |        |
| <3,000\(^{b}\)        | 81    | 58.91 ± 19.56   | 3.731     | 0.026*  | \(1\) > \(3\)* |
| 3,000~5,000\(^{b}\)   | 52    | 53.21 ± 19.20   |           |         |        |
| >5,000\(^{b}\)        | 23    | 47.39 ± 17.07   |           |         |        |
| Types of tumors        |       |                 |           |         |        |
| Head and neck\(^{b}\) tumor | 12 | 51.08 ± 19.16   | 1.966     | 0.121   |        |
| Chest tumor            | 48    | 60.88 ± 18.77   |           |         |        |
| Abdominal tumor        | 76    | 53.00 ± 20.16   |           |         |        |
| Pelvic tumor           | 20    | 53.30 ± 16.75   |           |         |        |
| Time since cancer diagnosis(month) |       |                 |           |         |        |
| 1~3\(^{b}\)           | 52    | 54.71 ± 19.21   | 2.923     | 0.036   | \(1\) < \(4\)* |
| 4~6\(^{b}\)           | 22    | 50.71 ± 16.80   |           |         | \(2\) < \(4\)** |
| 7~12\(^{b}\)          | 51    | 55.86 ± 20.00   |           |         |        |
| >12\(^{b}\)           | 31    | 63.52 ± 21.60   |           |         |        |

* reveals to \( p < 0.05 \); ** reveals to \( p < 0.01 \).
Table 4  Multiple stepwise regression analysis of patients (n=156)

| Items                        | β     | SE    | Standardized β | t    | p    |
|------------------------------|-------|-------|----------------|------|------|
| Constant                     | 60.311| 6.386 | 9.444          | 0.000|      |
| Place of residence           | 6.343 | 3.201 | 0.160          | 1.981| 0.049|
| Time since cancer diagnosis  |       |       |                |      |      |
| (reference≥12 months)        |       |       |                |      |      |
| 7~12months                   | -10.970| 4.160| -0.266         | -2.637| 0.009|
| Medical burden (reference=severe) | | | | | |
| None                         | -13.662| 6.719| -0.181         | -2.033| 0.044|
| Mild                         | -14.760| 4.901| -0.292         | -3.012| 0.003|
| Moderate                     | -8.096| 3.855| -0.209         | -2.100| 0.037|

R=0.647, R²=0.418, adjust R²=0.360, F=3.566, p<0.01.

The multiple stepwise regression analysis revealed that patients’ SPB was associated with place of residence (β=0.160, p=0.049), and time since cancer diagnosis with 7~12 months (β=-0.266, p=0.009), mild medical burden (β=-0.292, p=0.003) and moderate medical burden (β=-0.209, p=0.037) scores. The proportion of explained variance was 36.0%. Table 4 displays multiple linear regression analysis of patients’ SPB.

6. Discussion

This study aimed to explore the prevalence and the influencing factors of SPB among patients with advanced malignant tumors. We found that 90.3% of all patients who had advanced malignant tumors reported various levels of SPB, and over half of patients reported moderate to severe SPB (VAS≥50mm), indicating that the feeling of SPB was indeed prevalent among the participants. Multiple linear regression analysis suggested the SPB was most strongly associated with patients’ medical burden and the time since cancer diagnosis. The examined characteristics were associated weakly with SPB, only explaining about 36.0% of the variance. These results suggest that SPB is associated with characteristics that were not assessed in this study.

This study confirms the results of previous studies conducted among patients with chronic pain or terminally illness[9, 11], and one study has confirmed that more than one in three older patients with cancer may experience moderate to severe SPB at the time of chemotherapy initiation[13], by showing that patients with cancer who feel functionally or psychologically impaired may also experience SPB. SPB is a kind of obvious pressure directly faced by cancer patients, which can significantly affect the quality of life and long-term survival of patients, and health care professionals should carry out reasonable psychological and social intervention to reduce their SPB[14].

Our results have several clinical implications. Health care professionals should be aware that more than half of patients may experience moderate to severe SPB with advanced cancer. Professionals should thus be ready to address advanced cancer patients’ SPB, even when they are starting new treatment, and assess underlying factors and consequences in terms of patients’ adjustment to treatment and everyday life. When appropriate, health care professionals should also normalize this feeling and adapt their support to the needs of patients and caregivers. Future studies should investigate similarities and differences in patients’ and primary caregivers’ reports of SPB, and to better understand the family caregivers’ perception and may be helpful to organize the support of patient/primary caregiver dyad.

7. Conclusions

More than half of the SPB of patients with advanced malignant tumors in this group reveals to be the moderate to severe levels. And the influencing
Self-perceived Burden among Advanced Cancer Patients: A Cross-Sectional Survey

Factors of the SPB were place of residence, time since cancer diagnosis, medical burden. Health care workers must understand that patients with SPB often explore and make an effort to find ways in which they can reduce their family’s care giving burden and self-guilty. To respect their effort, health care workers should assist patients in performing self-care. Therefore, health care workers should not only assist patients’ efforts to cope with their stressful situation, but should also be together with them.

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Conflict of Interest

All authors declare no conflict of interest.

Reference

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