Concerns and Quality of Life of Cancer Survivors Across the Survivorship Trajectory: A Singapore Perspective

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Abstract

Background The aim of this study is to determine the main concerns of survivors at various stages of the cancer survivorship of the cancer survivorship trajectory and to assess whether these concerns have any effect on their quality of life (QOL). The overall goal was to use the insights from the study to guide practice on patient care.

Methods A cross-sectional survey of 1107 cancer survivors diagnosed with colorectal, breast, lung, gynaecological, prostate or liver cancers from a cancer centre in Singapore. Eligible patients self-completed a questionnaire adapted from the Mayo Clinic Cancer Centre’s Cancer Survivors Survey of Needs.

Results The top 5 concerns among all survivors were cancer treatment and recurrence risk (51%), followed by long-term treatment effects (49%), fear of recurrence (47%), financial concerns (37%) and fatigue (37%). Cancer treatment and recurrence risk, long-term treatment effects and fear of recurrence were amongst the top concerns across the survivorship trajectory. Mean QOL was 7.3 on a scale of 0 – 10. Completed treatment patients had higher QOL score than the newly diagnosed and on treatment patients and the patients dealing with recurrence or second cancer patients. Predictors for QOL included the economic status and housing type of patients and whether patients were concerned with pain and fatigue

Conclusion This study confirms that cancer survivors in Singapore face multiple challenges and had various concerns at various stages of cancer survivorship, some of which negatively affect their QOL. It is critical to design patient care delivery that appropriately address the various concerns of cancer survivors in order for them to cope and improve their QOL.

Background

The advent of technologies in the early detection and diagnosis of cancer with better treatment modalities and care have improved the survival rates of many cancer patients [1]. There are many definitions of cancer survivors. The biomedical definition of cancer survival refers to population of cancer patients who live disease-free for at least 5 years after treatment. In contrast, the National Coalition for Cancer Survivorship (NCCS) defines it as an individual from the time of cancer diagnosis
through the balance of his or her life [2].

Cancer survivors experience high level of physical, emotional, and social problems related to their cancer and treatment [3–7]. Besides the short-term adverse effects of cancer treatment, cancer treatment can also cause long-term (late) health effects. Late effects of cancer treatment include, but not limited to pain, chronic fatigue, lymphedema, peripheral neuropathy, cognitive impairment, infertility, cardiomyopathy, osteoporosis, including an increased risk of second primary cancers [8–13]. Cancer survivors also experienced persistent emotional and psychological issues relating to anxiety, depression, fears of recurrence and concerns regarding passing the disease to their offspring [14,15]. They also face a host of economic, financial, insurance and employment concerns [10,15,16].

These studies suggest that long-term consequences of cancer include not only lingering issues that present after diagnosis and treatment, but also new concerns that develop over time. These effects, while not life threatening, can affect day to day functioning and coping of cancer survivors and inadvertently affect their quality of life. It is therefore crucial to understand and address not only the immediate but also the long-term medical and psychosocial issues that confront cancer survivors as they transit across the survivorship trajectory.

The importance of identifying the most salient concerns the cancer survivors are experiencing in order to guide practice is a fundamental component of patient-centered care. According to the Institute of Medicine [17], besides effective patient education, empowerment, and communication, patient-centered care in the oncology setting also includes coordination and integration of care; and provision of emotional support as needed, such as relieving fear and anxiety and addressing mental health issues. Ascertaining the concerns of cancer survivors would aid healthcare professionals to provide survivors with timely and appropriate information and develop interventions to better address and manage these concerns. This could potentially enhance their coping skills, alleviate survivors’ psychologic distress about these concerns, improve satisfaction with care delivery, and exert a positive effect on their quality of life [18,19]. Although cancer is the leading cause of morbidity and mortality in Singapore [20], however, there is a dearth of information with regard to cancer survivors in Singapore. As most of the published studies on survivors’ concerns were conducted outside of
Singapore, the generalizability of the recommendations from these studies on how to address the survivors’ concerns and improve delivery of survivorship care to the Singapore healthcare system is limited. Furthermore, small sample size [21], a focus on cancer types [10,11,22,23] and age [24–26] are other limiting factors to previous studies in their application to Singapore.

The primary aim of this study is to establish the main concerns survivors of the across the cancer trajectory, and the secondary aim is to assess whether these concerns have any effect on their Quality of Life (QOL). The overall goal was to use the insights from the study to guide practice on patient care. Educational and psychosocial support services can be designed and targeted to address survivors’ key concerns so as to enhance coping skills and improve their quality of life.

Methods
Participants and Settings
In this study, a cancer survivor was defined as an individual from the time of cancer diagnosis through the balance of the individual’s lifespan according to the NCCS. Participants were at least 21 years old, able to read and write English or Chinese, did not have major intellectual or psychiatric impairment, and diagnosed with either colorectal, breast, lung, gynaecological, prostate or liver cancer (the top 6 cancers in Singapore). A cross-sectional survey was conducted at the specialist outpatient clinics and the clinics at the radiation oncology department in the National Cancer Centre Singapore, which sees the majority of the public sector oncology cases in Singapore [27]. All eligible patients were invited to take part in the survey during their first visit to the cancer center from mid-April to mid-July 2017.

Instruments
The self-administered questionnaire used in the survey was based on the “Cancer Survivors Survey of Needs” developed by the Mayo Clinic Cancer Centre [28]. The instrument was developed based on extensive literature reviews and pilot tested. Content validity was established through review by members of the Cancer Education Network. The questionnaire was translated to Chinese and verified by two staff who were competent in both English and Chinese languages. Five domains of concerns were covered in the questionnaire viz. (1) physical (20 issues), (2) emotional (14 issues), (3) social (7 issues), (4) spiritual (4 issues), and (5) others (6 issues). The issues covered in each domain were the same as those in the original survey from the Mayo clinic, except for the additional of one issue on
“Cancer treatment and recurrence risk” under the others domain. Respondents assessed the level of concern on each issue in the past 1 week prior to the survey using a 5-point Likert scale (Not concerned, Not really concerned, Neither unconcerned nor concerned, Concerned and Very concerned). The questionnaire also contained open-ended questions where respondents were asked to share on their primary source of strength during their cancer experience and what was their primary concern regarding their healthcare needs. In addition, respondents also rated their overall QOL in the past 1 week prior to the survey from 0 (as bad as it can be) to 10 (as good as it can be).

Study Procedure
Prior to each patient’s first clinic visit during survey period, research assistants reviewed the patient’s medical records and performed pre-screening. A copy of the survey form together with an explanatory note containing detailed explanation of the study purpose and procedure on how to complete the questionnaire were attached to the patient’s medical case sheet for each potential eligible patient. The clerical staff of the clinics in the cancer center confirmed the eligibility criteria of each patient and invited only those eligible ones to participate. Participation in the survey was voluntary and completion of survey form indicated patient’s consent to participate in the study. No identifiable data of the respondents was obtained.

Ethics and Consent to Participate
Ethical consent was obtained from the SingHealth Centralised Institutional Review Board (CIRB) prior to the study. Waiver of written informed consent was obtained as no personal identifiers of respondents were obtained.

Data Analysis
Data were analysed for the entire cohort of respondents, and by cancer survivorship stages. The cancer survivorship stages included in these further analyses were selected and grouped based on the clinical significance and the number of patients in the stage: patients who were newly diagnosed and on treatment (NT), patients who had completed treatment or were cancer-free ≥5 years (CT), and patients dealing with recurrence or second cancer (RS).

Patient characteristics at baseline were summarized as median (interquartile range) or frequency (percentage). Differences in mean QOL score between 2 groups of patients were compared using
independent T-tests. Logistic regression models were fitted to assess the association of various variables with patients reporting ≥ 1 concerned or very concerned issue. Linear regression models were fitted to identify the variables associated with QOL. Statistically significant variables with p<0.05 in the univariate analyses were entered into the multivariable regression analyses. All reported p-values were 2-sided, and a p-value <0.05 was considered statistically significant. All analyses were performed using SAS version 9.4 [29].

Results
Patient Characteristics
A total of 1107 patients filled in the survey form, of which 248 were NT (22%), 687 were CT (62%) and 96 were RS (8.7%). Median age of all patients was 61 years (range, 21—89 years) and two-thirds was female (Table 1). Majority of the patients were married (75%), had secondary and above qualifications (78%), and were either employed (43%) or retirees (34%). Patients across the cancer survivorship stages were similar in these characteristics. The commonest cancer site was in the breast (40%), followed by colorectal (22%) and lung (14%). Compared with the CT and RS patients, there were proportionately fewer breast cancers (32% NT vs 43% CT vs 42% RS) and more lung cancers (22% NT vs 10% CT vs 12% RS) amongst the NT patients.

Concerns
Based on the entire cohort, the issue with the highest percentage of patients reporting that they were concerned or very concerned with was cancer treatment and risk of recurrence (51%), followed by long-term treatment effects (49%), fear of recurrence (47%), fatigue (37%) and financial concerns (37%) (Table 2). Some of the prevalent concerns were common across the cancer survivorship stages. Cancer treatment and recurrence risk, long-term treatment effects and fear of recurrence were amongst the top 5 concerns reported by patients in each cancer survivorship stage. CT and RS patients who had received cancer treatment previously were also highly concerned with fatigue, while NT and RS patients who were either currently undergoing or going to receive treatment were highly concerned about their finances. In addition, NT and CT patients were also highly concerned with keeping their primary care physician informed of their cancer treatment and recurrence risk. When patients were broken down by various patient characteristics within each cancer survivorship stage,
the most prevalent concern reported by patients in each characteristic subgroup remained largely the same as that reported by all the patients in the survivorship stage (data not shown).

3.3. Risk Factors for Reporting At Least One Issue of Concern
Risk factors for patients to report at least one issue of concern were listed in Table 3. RS patients were more likely than CT patients to report at least one issue of concern overall and in each domain. Excluding the spiritual domain, patients who had chemotherapy were also more likely to report at least one issue of concern in each of the remaining domain and overall. Notably, tumour type was not a significant predictor for presence of at least one issue of concern amongst patients in this study.

3.4. Quality of Life
The overall mean QOL score was 7.3 with a standard deviation (SD) of 2.1. CT patients had higher QOL score (mean ± SD: 7.6 ± 1.9) than the NT patients (6.9 ± 2.2) and the RS patients (6.7 ± 2.5). The mean QOL scores of patients who had concerns in each of the non-spiritual domain were significantly lower than those of their counterparts who were not concerned (Table 4). On multivariable linear regression analysis, predictors for QOL included the economic status and housing type of patients and whether patients were concerned with pain and fatigue (Table 5). Patients who had pain and fatigue concerns reported QOL scores that were about 1 point lower than those who did not have such concerns. Cancer survivorship stages were not independently associated with QOL.

Discussion
In this study, we found that the top most concerns of entire cohort of cancer survivors were cancer treatment and the risk of recurrence, long-term treatment effects, fear of recurrence, financial concerns and fatigue. A few of these issues, such as cancer treatment and recurrence risk and long-term treatment effects were key concerns among patients throughout the whole cancer trajectory. The study also revealed that patients who were newly diagnosed and on treatment and those who had completed treatment or on follow-up were also concerned about keeping their primary care physician informed about their treatment and recurrence risk.

Cancer treatment related acute and late side effects have been well reported in the literature [3,5,8-12,14,15,30]. It has also been reported that even 20 years after stopping cancer treatment, the risks of recurrence (distant or contralateral breast) was present [31]. In our study, the fear of recurrence
(FOR) was the top emotional concern among the cancer survivors and also throughout the cancer trajectory. This finding has also been reported by other studies [14,21,32–40]. Evidence in literature reveals the negative impacts associated with FOR, including emotional distress [41], functional status [42] and quality of life [42–45]. Unlike other studies, we find that higher FOR is not associated with poorer quality of life of survivors. A recent study by Cho and Park [46] on 292 adolescent and young adult cancer survivors found that the negative association between FOR and mental health-related quality of life (HRQOL) was moderated by perceived growth (such as relating to others, personal growth, new possibilities, appreciation of life and spiritual life). In view of the moderating effects of perceived growth on the FOR-HRQOL links, enhancing on the growth perception may also be an strategy worth considering. As our study only measured the respondents’ overall quality of life and we did not measure the perceived growth, this finding warrants further study.

Based on current evidence, cancer treatment with its inherent side effects and whether it is efficacious and the FOR are the most distressing concerns in cancer patients throughout their cancer trajectory warrant the monitoring for the acute and long-term effects and underscores the importance of creating an information and supportive care environment that addresses survivors’ information needs and emotional support over time. This could also include assessments for symptoms and distress, and the adoption of the use of survivorship care plans ( SCPs) [47,48]. SCPs have been recommended by the Institute of Medicine (IOM) [49] as a tool to assist cancer survivors transit from cancer treatment to follow-up care through educating survivors and providers with comprehensive health information and resources [48]. This would also potentially address their concern about the integration of survivorship care between oncology and primary care settings.

Financial concerns were amongst the top concerns for patients who were either undergoing or about to undergo treatment in this study. As demonstrated in other studies, financial burden of cancer treatment is high and respondents expressed a great deal of worry about financial matters [38,45,50,51]. Cancer, its treatment, or the lasting effects of treatment can take a financial toll on the cancer survivors. The most financially impacted and at risk of going into debt are the adolescence and young adult [52]. In our study, those with lower economic status including those staying in Housing
Development Board (HDB) housing type are at higher risk of poorer QOL. Evidence [32,40,53] also indicates that increased financial burden as a result of cancer care costs is the strongest independent predictor of poor quality of life and adverse psychological issues such as depression, anxiety, and distress [53,54] among cancer survivors. As quality of life is negatively affected by financial burden, early identification of at risk patients and referrals to financial support services may help lessen this concern. At the state level, efforts to manage the escalating cost of cancer treatment, provision of better financial coverage and support and addressing the aspect of unemployment of cancer patients would be needed.

Fatigue was the most prevalent physical concern and one of the predictors for QOL of patients in this study. Cancer-related fatigue is a well-established concern for cancer survivors [8,32,34,37-39,45,55,56]. Fatigue reduces QOL by affecting a patient’s self-concept, appetite, activities of daily living, employment, social relationships and compliance with medical treatment [8,37,55,57], and may lead to treatment discontinuation and reduced survival [58]. Our study also found that fatigue was a major concern of the longer term cancer survivors which suggested that fatigue might have some lingering effect after cancer treatment. Bower’s [58] review suggests that approximately slightly more than a quarter cancer survivors experienced persistent fatigue through 10 years after cancer diagnosis and that is underreported by patients and undertreated by clinicians. Currently, little is known about the actual mechanisms that cause fatigue in cancer survivors. Nevertheless, the negative association between fatigue concern and QOL warrants more effective fatigue assessment, education and monitoring of patients in order to increase their functional capacity and self-care ability after cancer treatment.

Besides fatigue, this study also found that patients who had physical concerns of pain, had poorer QOL. Pain is one of the most feared, distressing and burdensome symptoms in cancer patients [59,60]. Uncontrolled pain affects functional capacity of cancer patients and hinders the ability to have control over their activities and enjoy their everyday life [61]. Our findings are consistent with other studies. For instance, Heydarnejad et al. [57] found that QOL of patients undergoing chemotherapy was lower in patients with pain than to those who had no pain. As uncontrolled pain
can have a detrimental effect on the patient’s QOL, and adequate management of cancer pain is crucial in improving the physical functioning of the cancer patients and their QOL, therefore assessment and monitoring of pain over the entire cancer trajectory are also critical for clinical identification of patients who might benefit from enhanced medical attention resulting in an improved QOL.

The finding that patients who had chemotherapy were more likely to report at least one issue of concern in all the domains except the spiritual domain may indicate that many patients experience side effects of chemotherapy. The side effects of chemotherapy are well reported in the literature [3,5,30,62]. As some side effects can be serious and life threatening, the finding also highlights the importance of establishing and monitoring these side effects during treatment and throughout their cancer trajectory.

This study also found significant difference in QOL between patients who were concerned with the most prevalent issue and those who were not for the newly diagnosed and recurrence patients, but not within those who had completed treatment. It is not surprising that newly diagnosed and recurrence patients’ QOL is more significantly affected as these are vulnerable times in the survivorship trajectory and the psychological distress confronting them is well reported in the literature [4,63–65]. This finding also underscores the importance of creating an environment that assesses, monitors and supports the information and supportive care needs for these at risk patients. This is critical as well informed and supported patients have been associated with many positive outcomes, including, increased patient involvement in decision making, increased satisfaction with treatment decisions, enhanced coping during the diagnostic, treatment and post treatment phases of illness, decreased anxiety and mood disturbances, and less emotional distress [18,19,23,66–68].

Limitations

There are several limitations in this cross-sectional survey of perceived concerns among a selective group of cancer survivors at a specific point in time in the trajectory and a non-validated questionnaire for the study population. Longitudinal studies of cancer survivors’ needs and their
concerns throughout their survivorship trajectory would provide more complete insights on the changes in concerns at different times in the continuum of care. Identifying the ongoing and changing concerns of cancer survivors especially as they transit away from the treatment phase remains a key challenge for survivorship study. To partly overcome this limitation, we analysed the survey data according to key time points of cancer survivorship such as during treatment, treatment completion and recurrence instead of variable such as time since cancer diagnosis.

The study sample included only patients diagnosed with colorectal, breast, lung, gynaecological, prostate or liver cancer from a single cancer centre, and this might limit the generalization of the results to other settings. There were also proportionately more breast cancer survivors who participated in the survey, which suggested that the data might underrepresent the concerns of cancer survivors with the other cancer types. To limit these effects, we reported the survey results based on the overall cohort and by cancer survivorship stages instead of breaking down the analyses by cancer sites.

In spite of these limitations, given the large sample of the top 6 most common cancers in Singapore, we believe that our study has added valuable insights on the concerns of cancer survivors treated in an Asian cancer centre. It also helped prioritize which are the concerns that should be the focus of prevention and remediation efforts in our patient care delivery. To our knowledge, this is the first study determining the concerns of cancer survivors in Singapore.

Conclusions
The study concludes that cancer survivors in Singapore face multiple challenges and had various concerns at various stages of cancer survivorship, some of which negatively affect their QOL. As better-informed patients are more able to cope, more satisfied with their care and do better clinically, it is critical that sufficient resources be allocated to develop appropriate strategies to address the key areas of concerns of cancer survivors. Important areas to address include symptom assessments and management, adoption of distress screening tools at each transition of survivorship trajectory, and development of education materials and psychosocial support services relating to the various identified concerns, with the main ones being the long-term effects of cancer treatment, risks of
cancer recurrence, fatigue, and financial support and resources.

Another strategy worth considering is the adoption of the SCP which is highly recommended by the IOM. Such care plans could potentially enable the survivors to play an active role in the management of long-term effects of their cancers and provide an effective communication tool for their primary healthcare providers to provide appropriate care to these survivors. Finally, a periodic audit of the concerns of survivors and how well their needs are met should be conducted under a patient-centered approach in understanding and addressing the unique and evolving concerns of cancer survivors across the survivorship trajectory.

Abbreviations
NCCS: National Coalition for Cancer Survivorship; QOL: Quality of Life; NT: Newly diagnosed and on treatment; CT: Completed treatment or were cancer-free ≥5 years; RS: Recurrence or second cancer; SD: Standard deviation; FOR: Fear of recurrence; HRQOL: Health-related Quality of Life; SCP: Survivorship Care Plan; IOM: Institute of Medicine.

Declarations
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Authors’ contributions
CGP conceptualised and designed the study. Data collection was managed by CGP. OWS performed data cleaning and statistical analysis. NQS and THK supervised and provided guidance and expertise.

All authors read and approved the final manuscript.

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Availability of data and materials
All data supporting the findings of this study are available within the article.

Ethics approval and consent to participate
Ethical consent was obtained from the SingHealth Centralised Institutional Review Board (CIRB) prior
to the study. Waiver of written informed consent was obtained as no personal identifiers of respondents were obtained.

Consent for Publication
Not applicable.

Competing Interest
The authors have no conflict of interest to declare.

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Tables
Table 1. Patient characteristics
|                                | All^ (N=1107) | NT (N=248) | CT (N=687) |
|--------------------------------|--------------|------------|------------|
| Age, years                     |              |            |            |
| Below 60                       | 451 40.7    | 104 41.9   | 277 40.3   |
| 60 and over                    | 555 50.1    | 131 52.8   | 346 50.4   |
| Missing                        | 101 9.1     | 13 5.2     | 64 9.3    |
| Median (interquartile range)*  | 61 (51 - 68) | 61 (50 - 68) | 61 (52 - 68) |
| Gender                         |              |            |            |
| Female                         | 728 65.8    | 149 60.1   | 466 67.8   |
| Male                           | 369 33.3    | 99 39.9    | 220 32.0   |
| Missing                        | 10 0.9      | 0 -        | 1 0.1     |
| Ethnic group                   |              |            |            |
| Chinese                        | 936 84.6    | 213 85.9   | 589 85.7   |
| Malays                         | 69 6.2      | 17 6.9     | 40 5.8    |
| Indians                        | 45 4.1      | 7 2.8      | 33 4.8    |
| Others                         | 38 3.4      | 10 4.0     | 19 2.8    |
| Missing                        | 19 1.7      | 1 0.4      | 6 0.9     |
| Marital status                 |              |            |            |
| Single                         | 175 15.8    | 47 19.0    | 97 14.1   |
| Married                        | 829 74.9    | 183 73.8   | 529 77.0   |
| Divorced / Separated           | 51 4.6      | 11 4.4     | 33 4.8    |
| Widowed                        | 40 3.6      | 7 2.8      | 26 3.8    |
| Missing                        | 12 1.1      | 0 -        | 2 0.3     |
| Education                      |              |            |            |
| No formal education            | 46 4.2      | 10 4.0     | 29 4.2    |
| Primary                        | 187 16.9    | 46 18.5    | 114 16.6   |
| Secondary                      | 414 37.4    | 91 36.7    | 266 38.7   |
| Post-secondary                 | 201 18.2    | 47 19.0    | 134 19.5   |
| Tertiary                       | 246 22.2    | 54 21.8    | 142 20.7   |
| Missing                        | 13 1.2      | 0 -        | 2 0.3     |
| Economic status                |              |            |            |
| Employed                       | 478 43.2    | 103 41.5   | 315 45.9   |
| Unemployed                     | 84 7.6      | 24 9.7     | 37 5.4    |
| Homemaker                      | 156 14.1    | 34 13.7    | 99 14.4    |
| Student                        | 3 0.3       | 1 0.4      | 2 0.3     |
| Retired                        | 373 33.7    | 85 34.3    | 231 33.6   |
| Missing                        | 13 1.2      | 1 0.4      | 3 0.4     |
| Housing type                   |              |            |            |
| HDB                            | 866 78.2    | 205 82.7   | 533 77.6   |
| Private housing                | 212 19.2    | 37 14.9    | 143 20.8   |
| Missing                        | 29 2.6      | 6 2.4      | 11 1.6    |
| Cancer type                    |              |            |            |
| Breast                         | 438 39.6    | 78 31.5    | 294 42.8   |
| Colorectal                     | 242 21.9    | 59 23.8    | 148 21.5   |
| Lung                           | 152 13.7    | 54 21.8    | 68 9.9    |
| Gynecological                  | 109 9.8     | 15 6.0     | 79 11.5    |
| Prostate                       | 119 10.7    | 32 12.9    | 75 10.9    |
| Liver                          | 32 2.9      | 8 3.2      | 20 2.9    |
| Missing                        | 15 1.4      | 2 0.8      | 3 0.4     |
| Years since diagnosis          |              |            |            |
| ≤1 year                        | 362 32.7    | 172 69.4   | 148 21.5   |
| 2 - 5 years                    | 407 36.8    | 52 21.0    | 289 42.1   |
| ≥6 years                       | 245 22.1    | 0 -        | 200 29.1   |
| Missing                        | 93 8.4      | 24 9.7     | 50 7.3    |
| Median (interquartile range)*  | 2 (1 - 6)   | 1 (1 - 2)  | 3 (2 - 7) |
| Treatment received             |              |            |            |
| Surgery                        | 781 70.6    | 126 50.8   | 544 79.2   |
| Radiation                      | 563 50.9    | 89 35.9    | 407 59.2   |
| Chemotherapy                   | 727 65.7    | 189 76.2   | 430 62.6   |
| Hormonal therapy              | 159 14.4    | 51 20.6    | 83 12.1    |
| Others                         | 36 3.3      | 18 7.3     | 14 2.0    |

NT, newly diagnosed, on treatment; CT, completed treatment / cancer-free ≥ 5 years; RS, had
recurrence / second cancer

^ Includes patients on palliative care

* Among patients with non-missing values

Table 2. Issue of concern
| Domain and issue | All^ (N=1107) | NT (N=248) |
|------------------|---------------|------------|
| **1 Physical**   |               |            |
| 1.01 Pain        | 317 (28.6)    | 70 (28.2)  |
| 1.02 Fatigue     | 413 (37.3)    | 134 (54.1) |
| 1.03 Sleep       | 356 (32.2)    | 89 (35.7)  |
| 1.04 Memory      | 271 (24.5)    | 24 (9.7)   |
| 1.05 Nausea / Vomiting | 155 (14.0) | 49 (19.8)  |
| 1.06 Poor appetite | 162 (14.6) | 40 (16.1)  |
| 1.07 Trouble swallowing | 108 (9.8) | 46 (18.1)  |
| 1.08 Dental and mouth problems | 177 (16.0) | 45 (18.1)  |
| 1.09 Weight changes | 275 (24.8) | 70 (28.2)  |
| 1.10 Balance / Walking / Mobility | 263 (23.8) | 64 (25.8)  |
| 1.11 Loss of strength | 374 (33.8) | 70 (28.2)  |
| 1.12 Tingling and numbness in feet and hands | 353 (31.9) | 89 (35.9)  |
| 1.13 Swelling of legs and arms | 196 (17.7) | 45 (18.1)  |
| 1.14 Osteoporosis / Bone health | 320 (29.5) | 37 (14.9)  |
| 1.15 Hair and skin care issues | 293 (26.5) | 89 (35.9)  |
| 1.16 Body changes | 246 (22.2) | 68 (27.4)  |
| 1.17 Bowel or bladder changes | 281 (25.4) | 66 (26.6)  |
| 1.18 Sexual issues | 105 (9.5) | 22 (8.9)   |
| 1.19 Fertility issues | 71 (6.4) | 18 (7.3)   |
| 1.20 Hot flashes / Menopause | 125 (11.3) | 31 (12.5)  |
| **2 Emotional**  |               |            |
| 2.01 Defining a new sense of normal | 220 (19.9) | 76 (30.6)  |
| 2.02 Managing difficult emotions | 267 (24.2) | 72 (29.0)  |
| 2.03 Coping with grief and loss | 193 (17.4) | 53 (21.4)  |
| 2.04 Living with uncertainty | 317 (28.6) | 74 (29.8)  |
| 2.05 Fear of recurrence | 515 (46.5) | 113 (45.6) |
| 2.06 Managing stress | 257 (23.2) | 62 (25.0)  |
| 2.07 Isolation / Feeling alone | 179 (16.2) | 49 (19.8)  |
| 2.08 Intimacy issues | 91 (8.2) | 20 (8.1)   |
| 2.09 Looking for the brighter side | 286 (25.8) | 82 (33.1)  |
| 2.10 Having a sense of well being | 276 (24.9) | 79 (31.9)  |
| 2.11 Changing relationships with spouse, family and others | 143 (12.9) | 36 (14.5)  |
| 2.12 Finding support resources | 204 (18.4) | 63 (25.4)  |
| 2.13 Connecting to counselling services | 113 (10.2) | 34 (13.7)  |
| 2.14 Genetic counselling (worry about children getting cancer) | 305 (27.6) | 64 (25.8)  |
| **3 Social**     |               |            |
| 3.01 Managing household activities | 210 (19.0) | 56 (22.6)  |
| 3.02 Caring for family members | 247 (22.3) | 64 (25.8)  |
| 3.03 Talking about cancer with family and friends | 195 (17.6) | 54 (21.8)  |
| 3.04 Returning to work | 196 (17.7) | 60 (24.2)  |
| 3.05 Health insurance | 327 (29.5) | 92 (37.1)  |
| 3.06 Financial concerns | 406 (36.7) | 116 (46.8) |
| 3.07 Debt from medical bills | 280 (25.3) | 78 (31.5)  |
| **4 Spiritual**  |               |            |
| 4.01 Religious or spiritual support | 186 (16.8) | 49 (19.8)  |
| 4.02 Religious or spiritual distress | 85 (7.7) | 13 (5.2)   |
| 4.03 Loss of faith | 62 (5.6) | 9 (3.6)    |
| 4.04 End of life concerns | 149 (13.5) | 35 (14.1)  |
| **5 Others**     |               |            |
| 5.01 Staying connected with the medical system | 331 (29.9) | 87 (35.1)  |
| 5.02 Who to call for medical problems | 296 (26.7) | 69 (27.8)  |
| 5.03 Keeping primary care physician informed of cancer treatment and recurrence risk | 397 (35.9) | 105 (42.3) |
| 5.04 Use of complementary or alternative therapies | 273 (24.7) | 65 (26.2)  |
| 5.05 Cancer treatment and recurrence risk# | 566 (51.1) | 126 (50.8) |
| 5.06 Concern about long-term effects of treatment | 540 (48.8) | 147 (59.3) |

NT, newly diagnosed, on treatment; CT, completed treatment / cancer-free ≥ 5 years; RS, had recurrence / second cancer

^ Includes patients on palliative care

* Tie with at least one other issue within the patient cohort
# New question added to the original questionnaire from Mayo clinic

Table 3. Multivariable logistic regression for the presence of at least one issue of concern

| Domain | Variables | Categories | OR (95% CI) |
|--------|-----------|------------|-------------|
| Overall | Cancer survivorship stages | CT vs RS | 0.23 (0.11 - 0.51) |
|         | NT vs RS | 2.77 (0.34 - 22.85) |
|         | Others vs RS | 0.33 (0.10 - 1.11) |
|         | Chemotherapy | No vs Yes | 0.46 (0.30 - 0.70) |
| Physical | Years since diagnosis | ≤1 year vs ≥6 years | 1.85 (1.20 - 2.85) |
|         | 2-5 years vs ≥6 years | 1.30 (0.90 - 1.86) |
|         | Cancer survivorship stages | CT vs RS | 0.49 (0.31 - 0.78) |
|         | NT vs RS | 1.29 (0.61 - 2.73) |
|         | Others vs RS | 0.85 (0.36 - 2.01) |
|         | Chemotherapy | No vs Yes | 0.55 (0.41 - 0.75) |
| Emotional | Cancer survivorship stages | CT vs RS | 0.60 (0.42 - 0.86) |
|         | NT vs RS | 1.77 (0.91 - 3.44) |
|         | Others vs RS | 0781 (0.40 - 1.53) |
|         | Surgery | No vs Yes | 0.73 (0.53 - 0.99) |
|         | Chemotherapy | No vs Yes | 0.55 (0.42 - 0.73) |
| Social | Age | per year increase | 0.98 (0.97 - 0.99) |
|         | Cancer survivorship stages | CT vs RS | 0.55 (0.40 - 0.76) |
|         | NT vs RS | 1.39 (0.80 - 2.42) |
|         | Others vs RS | 2.14 (1.02 - 4.49) |
|         | Chemotherapy | No vs Yes | 0.67 (0.50 - 0.88) |
| Spiritual | Gender | Female vs Male | 1.61 (1.16 - 2.21) |
|         | Race | Malay vs Chinese | 3.67 (2.19 - 6.16) |
|         | Indian vs Chinese | 2.18 (1.14 - 4.18) |
|         | Others vs Chinese | 1.53 (0.70 - 3.35) |
|         | Cancer survivorship stages | CT vs RS | 0.61 (0.43 - 0.87) |
|         | NT vs RS | 1.45 (0.86 - 2.45) |
|         | Others vs RS | 1.76 (0.90 - 3.42) |
| Others | Cancer survivorship stages | CT vs RS | 0.51 (0.36 - 0.72) |
|         | NT vs RS | 1.03 (0.57 - 1.87) |
|         | Others vs RS | 1.77 (0.74 - 4.20) |
|         | Chemotherapy | No vs Yes | 0.68 (0.51 - 0.90) |

OR, odds ratio; CI, confidence interval; NT, newly diagnosed, on treatment; CT, completed treatment / cancer-free ≥ 5 years; RS, had recurrence / second cancer
Table 4. QOL scores

| Domain and issue# | All^ (N=1107) | NT (N=248) |
|------------------|---------------|-----------|
|                  | C Mean (SD)   | NC Mean (SD) | diff |
|                  |               |            |      |
| **1 Physical**   |               |            |      |
| 1.01 Pain        | 6.3 (2.4)     | 7.7 (1.8)  | 1.4***|
| 1.02 Fatigue     | 6.4 (2.2)     | 7.9 (1.7)  | 1.5***|
| 1.03 Sleep disturbances | 6.6 (2.3) | 7.6 (1.9)  | 1.0***|
| 1.04 Memory & concentration | 6.6 (2.3) | 7.5 (2.0)  | 0.9***|
| 1.05 Nausea / Vomiting | 6.4 (2.4) | 7.4 (2.0)  | 1.0***|
| 1.06 Poor appetite | 6.2 (2.5) | 7.5 (1.9)  | 1.3***|
| 1.07 Trouble swallowing | 6.7 (2.5) | 7.3 (2.0)  | 0.6* |
| 1.08 Mouth problems | 6.0 (2.3) | 7.4 (2.0)  | 0.6** |
| 1.09 Weight changes | 6.5 (2.4) | 7.5 (1.9)  | 1.0** |
| 1.10 Balance / Mobility | 6.4 (2.4) | 7.6 (1.9)  | 1.2** |
| 1.11 Loss of strength | 6.4 (2.3) | 7.7 (1.8)  | 1.3***|
| 1.12 Numbness in feet & hands | 6.8 (2.3) | 7.5 (1.9)  | 0.7***|
| 1.13 Swelling of legs and arms | 6.8 (2.4) | 7.4 (2.0)  | 0.6** |
| 1.14 Bone health | 6.9 (2.2) | 7.4 (2.0)  | 0.5** |
| 1.15 Hair & skin care issues | 6.8 (2.1) | 7.5 (2.0)  | 0.7***|
| 1.16 Body changes | 6.5 (2.4) | 7.5 (1.9)  | 1.0***|
| 1.17 Bowel or bladder changes | 6.7 (2.3) | 7.5 (2.0)  | 0.8***|
| 1.18 Sexual issues | 7.3 (2.2) | 7.3 (2.1)  | 0    |
| 1.19 Fertility issues | 7.4 (2.1) | 7.3 (2.1)  | -0.1 |
| 1.20 Hot flashes / Menopause | 7.1 (2.1) | 7.3 (2.1)  | 0.2  |
| **2 Emotional**  |               |            |      |
| 2.01 A new sense of normal | 6.3 (2.3) | 7.5 (1.9)  | 1.2***|
| 2.02 Manage difficult emotions | 6.4 (2.3) | 7.6 (1.9)  | 1.2***|
| 2.03 Coping with grief and loss | 6.2 (2.4) | 7.5 (2.0)  | 1.3***|
| 2.04 Living with uncertainty | 6.6 (2.3) | 7.6 (1.9)  | 1.0***|
| 2.05 Fear of recurrence | 7.0 (2.1) | 7.6 (2.0)  | 0.6***|
| 2.06 Managing stress | 6.5 (2.4) | 7.5 (2.0)  | 1.0***|
| 2.07 Isolation / Feeling alone | 6.4 (2.4) | 7.5 (2.0)  | 1.1***|
| 2.08 Intimacy issues | 6.8 (2.1) | 7.3 (2.1)  | 0.5  |
| 2.09 Looking for the brighter side | 6.7 (2.3) | 7.5 (2.0)  | 0.8***|
| 2.10 A sense of well being | 6.9 (2.4) | 7.4 (2.0)  | 0.5** |
| 2.11 Changing relationships | 7.0 (2.3) | 7.3 (2.1)  | 0.3  |
| 2.12 Finding support resources | 6.6 (2.5) | 7.4 (1.9)  | 0.8***|
| 2.13 Counselling services | 6.7 (2.4) | 7.4 (2.0)  | 0.7** |
| 2.14 Genetic counselling | 7.1 (2.1) | 7.4 (2.1)  | 0.3* |
| **3 Social**     |               |            |      |
| 3.01 Household activities | 6.9 (2.2) | 7.8 (1.8)  | 0.9***|
| 3.02 Caring for family members | 6.8 (2.4) | 7.4 (2.0)  | 0.8***|
| 3.03 Talking about cancer | 6.8 (2.3) | 7.4 (2.0)  | 0.6** |
| 3.04 Returning to work | 6.7 (2.2) | 7.4 (2.0)  | 0.7** |
| 3.05 Health insurance | 6.9 (2.2) | 7.4 (2.0)  | 0.5** |
| 3.06 Financial concerns | 6.7 (2.4) | 7.6 (1.8)  | 0.9***|
| 3.07 Debt from medical bills | 6.7 (2.4) | 7.5 (1.9)  | 0.8***|
| **4 Spiritual**  |               |            |      |
| 4.01 Religious or spiritual support | 7.3 (2.0) | 7.3 (2.1)  | 0    |
| 4.02 Religious or spiritual distress | 7.2 (2.2) | 7.3 (2.1)  | 0.1  |
| 4.03 Loss of faith | 6.9 (2.6) | 7.3 (2.0)  | 0.4  |
| 4.04 End of life concerns | 6.9 (2.5) | 7.4 (2.0)  | 0.5* |
| **5 Others**     |               |            |      |
| 5.01 Connection with medical system | 7.2 (2.1) | 7.3 (2.1)  | 0.1  |
| 5.02 Who to call for medical problems | 7.1 (2.2) | 7.3 (2.0)  | 0.2  |
| 5.03 Keeping primary care physician informed | 7.0 (2.2) | 7.4 (2.0)  | 0.4**|
| 5.04 Use of complementary therapies | 6.9 (2.4) | 7.4 (2.0)  | 0.5** |
| 5.05 Treatment & recurrence risk | 7.1 (2.2) | 7.5 (1.9)  | 0.4**|
| 5.06 Long-term effects of treatment | 7.0 (2.1) | 7.6 (1.9)  | 0.6**|

QOL, quality of life; SD, standard deviation; NT, newly diagnosed, on treatment; CT, completed
treatment / cancer-free ≥ 5 years; RS, had recurrence / second cancer; C, concerned or very concerned with issue; NC, not concerned, not really concerned or neither concerned nor unconcerned
with issue

^ Includes patients on palliative care

# See Table 2 for the full description of each issue

* 0.01≤p<0.05  **0.001≤p<0.01  ***p<0.001

| Variable                   | Categories                | Beta estimate (SE) | p-value  |
|----------------------------|---------------------------|-------------------|----------|
| Constant                   | -                         | 8.25 (0.16)       | <0.001   |
| Economic status^           | Employed vs Retired       | 0.34 (0.14)       | 0.015    |
|                            | Unemployed vs Retired     | -0.37 (0.25)      | 0.134    |
|                            | Homemaker vs Retired      | 0.57 (0.20)       | 0.004    |
| Housing                    | HDB vs Private housing    | -0.61 (0.16)      | <0.001   |
| Physical issue: Pain       | C vs NC                   | -0.88 (0.15)      | <0.001   |
| Physical issue: Fatigue    | C vs NC                   | -1.07 (0.14)      | <0.001   |

QOL, quality of life; SE, standard error; C, concerned or very concerned with issue; NC, not concerned, not really concerned or neither concerned nor unconcerned with issue

^ Excludes 3 students from analysis as this small category of patients cannot be combined with the other categories of economic status appropriately