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ORIGINAL ARTICLE

# Illness perceptions among cancer survivors

**Na Zhang**[1] · **Richard Fielding**[1] · **Inda Soong**[2] · **Karen KK Chan**[3] · **Janice Tsang**[4] ·
**Victor Lee**[4] · **Conrad Lee**[5] · **Alice Ng**[6] · **Wing Kin Sze**[6] · **Pamela Tin**[1] ·
**Wendy Wing Tak Lam**[1]

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**Abstract**

*Purpose* The purpose of the study is to document in Hong Kong Chinese cancer survivors cross-sectional associations between illness perceptions, physical symptom distress and dispositional optimism.

*Methods* A consecutive sample of 1036 (response rate, 86.1 %, mean age 55.18 years, 60 % female) survivors of different cancers recruited within 6 months of completion of adjuvant therapy from Hong Kong public hospitals completed the Brief Illness Perception Questionnaire (B-IPQ), Chinese version of the Memorial Symptom Assessment Scale Short-Form (MSAS-SF), and the revised Chinese version of Life Orientation Test (C-LOT-R), respectively. Stepwise multiple regression analyses examined adjusted associations.

*Results* IPQ seriousness, symptom identity, illness concern, and emotional impact scores varied by cancer type ($p<0.01$). Stress-related, lifestyle, environment, psychological/personality, and health-related factors were most frequently attributed causes of cancer. After adjustment for sample differences, physical symptom distress was significantly associated with all illness perception dimensions ($p<0.01$), excepting control beliefs. Optimism was positively correlated with perceived personal and treatment control ($p<0.01$) and illness understanding ($p<0.01$), but negatively correlated with other IPQ dimensions (all $p<0.01$). IPQ domain differences by cancer type were eliminated by adjustment for sample characteristics.

*Conclusion* Illness perceptions did not differ by cancer type. Greater physical symptom distress and lower levels of optimism were associated with more negative illness perceptions.

*Implications* Understanding how cancer survivors make sense of cancer can clarify an important aspect of adaptation. This in turn can inform interventions to facilitate adjustment. Knowledge contributions include evidence of physical symptom distress correlating with most dimensions of illness perception. Optimism was also associated with cancer survivors' illness perceptions.

**Keywords** Illness perceptions · Symptom distress · Optimism · Cancer survivors · Chinese

As elsewhere, the number of new cancer cases is increasing in Hong Kong (HK) at an average annual rate of 2.5 % compared to the population growth rate of 0.6 % from 2002 to 2012. While much of this increase can be attributed to population ageing, the numbers are significant. In 2012, 27,848 new cancer cases were diagnosed in HK [1]. Improvements in cancer diagnosis and treatment and the younger ages at which cancer is now occurring mean that increasingly cancer patients will be long-term survivors. They face persisting difficulties with physical and psychological health as well as impaired quality

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✉ Wendy Wing Tak Lam
wwtlam@hku.hk

[1] Centre for Psycho-Oncology Research and Training, School of Public Health, The University of Hong Kong, 5/F, WMW Mong Block, Faculty of Medicine Building, 21 Sassoon Road, Pok Fu Lam, Hong Kong

[2] Department of Clinical Oncology, Pamela Youde Nethersole Eastern Hospital, Chai Wan, Hong Kong

[3] Department of Obstetrics and Gynecology, The University of Hong Kong, Pok Fu Lam, Hong Kong

[4] Department of Clinical Oncology, The University of Hong Kong, Pok Fu Lam, Hong Kong

[5] Department of Clinical Oncology, Princess Margaret Hospital, Kwai Chung, Hong Kong

[6] Department of Clinical Oncology, Tuen Mun Hospital, Tuen Mun, Hong Kong

of life, since the late effects of cancer treatment may last a lifetime [2–4] and poor adaptation to these escalate healthcare demand and costs. Patients' perceptions of their illness may influence illness outcomes [5]. Residual effects of cancer and its treatments can exert significant coping demand on survivors. Documenting links between cancer survivors' illness perceptions and adaptation outcomes can inform cost-effective targeted interventions minimizing distress and enhancing long-term survivorship care.

When diagnosed, individuals build new, or modify pre-existing cognitive models of their condition, illness representations [5, 6], individual schemas comprising knowledge, beliefs, and expectations about particular illnesses. These may "map" adaptive responses to illness-related demands. The terms "illness representation," "illness perceptions," "illness cognitions," or "health beliefs" are often used interchangeably [7]. However, an "illness representation" more specifically refers to an illness schema, such as might comprise all of a person's knowledge and beliefs about "cancer," whereas "illness perception" refers to the acquisition and subjectivity of the real-time experience of having cancer. Theoretical elements of representations gathered from third-party sources may pre-date the diagnosis (most people have an illness representation of cancer before having experienced it directly, which is modified on having the disease), but personal experience of disease adds important subjective elements that hierarchically range from the perceptually oriented concrete symptom experience, such as pain and fatigue, through to abstract emotional and symbolic elements such as causal attributions, perceived controllability, anticipated outcomes, and responses [8]. Consequently, symptom experience, both physical and psychological, defined as perceptions of an experience and its attribution as a symptom, of given frequency and severity, and any associated emotion, such as distress [9], strongly shapes illness representations [10] providing concrete components of illness experience and is reflexively modified by interpretive representation elements that influence perceptions. For example, pain perception is modified by catastrophic cognitions enhanced by negative affect [11, 12], whereas individuals who perceived more numerous or severe physical symptoms reported more negative illness perceptions [13, 14]. These directly experienced concrete and abstract elements may be incongruent with pre-existing representation elements, possibly generating distress by increased uncertainty or perceived lack of control, for example. Conversely, outcome expectation tendencies (optimism/pessimism) influence health outcomes [15–17]. Optimists are confident, expecting good outcomes about their future [18]. Optimistic patients with chronic illness report more positive and less negative illness perceptions [19, 20], feel their illness is more controllable [21], and experienced less negative emotional outcomes [22]. Complex interplays between these elements present response options output from the illness representation. Hence, outcome expectancies may influence mitigation against negative interpretations of concrete symptom experience.

Development of the most widely used measure of illness representations, the Illness Perception Questionnaire (IPQ) defined five key attributes of illness representations [6]: *Consequences* are perceived effects or outcomes of illness, potentially being good or bad, minor or major. *Timeline* reflects beliefs about the disease duration. *Identity* captures conceptions and symptoms or illness manifestations, labeled or named by the patients. *Control* beliefs reflect the extent to which disease can be controlled by both patients and treatments, respectively. *Causes* represent patients' causal attributions for the illness. Hence, the IPQ measures the more abstract components of an underlying illness representation.

While empirical studies of predominantly anglophone cancer patients have indicated that negative illness perceptions are significantly associated with more psychological distress and worse quality of life [23, 24], how non-anglophone ethnic groups make sense of cancer remains unclear. Many existing studies also omitted reporting causal beliefs, giving an incomplete picture of patients' illness perceptions. Because patients diagnosed with different cancer types have different histories, understandings, and illness experiences and given individuals' illness representations are shaped by knowledge, experiences, and personal characteristics [5, 6], patients' perceptions of their illness should vary by disease type. Of two studies comparing illness perception dimensions by different cancer types [25, 26], only common cancers of one type (colorectal [25] and breast [26]) were compared with less common cancers. Comparison of illness perceptions of cancers of different sites will help confirm their conclusions. It remains unknown whether differences among patients within a diagnostic group are as notable as those between different groups, reflecting the relative influences of pre-existing representations by demographics, versus those of the active disease in building representations. Also, very few studies have examined illness perceptions concurrently with physical symptom distress, a key domain of symptom experience. But because greater optimism is strongly related to lower symptom distress [15, 16], it is unknown if illness representations have an independent association with distress independent of optimism, and how optimism relates to each illness perception dimension after adjusting for potential confounders.

Here, we report cross-sectional associations between dimensions of illness perception, physical symptom distress, and optimism, after adjustment for sociodemographic and clinical characteristics among Hong Kong Chinese cancer survivors. We hypothesized that (a) illness perceptions would vary more between than within cancer types, (b) higher physical symptom distress would be associated with more negative illness perceptions, whereas (c) greater optimism positively correlated with more positive illness perceptions.

## Methods

### Sample and settings

As part of an ongoing longitudinal study of Chinese cancer survivors implemented after approval by university and public Hospital Authority ethics committees, a consecutive sample of patients was recruited from outpatient oncology clinics in eight Hong Kong public hospitals, between September 2010 and June 2013. The inclusion criteria were age ≥18 years, within 6 months of completing primary treatment, and Cantonese or Mandarin language fluency. Patients with hearing or cognitive impairment were excluded. Informed consent was obtained from all individual participants included in the study and interviewed face-to-face by experienced research assistant in the clinic setting.

### Measures

**Sociodemographic and medical characteristics** Sociodemographic data on age, gender, marital status, education level, occupation, and family income were collected during interview. Clinical characteristics (cancer type, stage, time since initial diagnosis, and treatment received) were extracted from medical records.

**Illness representations** Cognitive and emotional representations of illness were measured using the nine-item Brief Illness Perception Questionnaire (B-IPQ) [27]. Cognitive illness representations are assessed by five items addressing consequences (item 1: how much does your illness affect your life?), timeline (item 2: how long do you think your illness will continue?), personal control (item 3: how much control do you feel you have over your illness?), treatment control (item 4: how much do you think your treatment can help your illness?), and identity (item 5: how much do you experience symptoms from your illness?). Two items, concern (item 7: how well do you feel you understand your illness?) and emotions (item 8: how much does your illness affect you emotionally?), addressed emotional aspects of illness representations. Illness comprehensibility is assessed by one item: coherence (item 7: how well do you feel you understand your illness?). All items are rated on linear 0- to 10-point response scales except the open-ended casual question (item 9), which asks the patients to list three most important factors respondents believe have caused their illness. Higher scores indicate more negative illness representations, except for items 3, 4, and 7 where higher scores indicate more positive illness perceptions. The English version of B-IPQ showed acceptable test-retest reliability both after 3 weeks (Pearson's $r$, 0.48–0.70) and 6 weeks (Pearson's $r$, 0.42–0.75) and good concurrent validity [27]. The B-IPQ has been translated into Chinese [28] and used in Taiwanese [29] and Mainland Chinese populations [30].

**Physical symptom distress** Physical symptom distress was assessed by the Physical Symptom Distress subscale (PHYS) of Chinese version of the Memorial Symptom Assessment Scale Short-Form (MSAS-SF) [31]. The PHYS consists 12 prevalent physical symptoms, each recorded as present or absent during the past 7 days, and if present, any distress associated with that symptom is rated on a five-point (0–4) Likert scale: "Not at all," "A little bit," "Somewhat," "Quite a bit," and "Very much" and scored from 0.8 to 4.0, with higher scores indicating higher distress. The Chinese version of the MSAS-SF has been validated in Chinese cancer population, and all the subscales have demonstrated good reliability (Cronbach's $\alpha$ 0.84–0.91) and validity [31].

**Optimism** Optimism was measured by the six-item revised Chinese version of Life Orientation Test (C-LOT-R). Three items measure positive and three items measure negative outcome expectancies, each rated on a four-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). Although the Cronbach's $\alpha$=0.61 was lower than the suggested acceptable level of 0.65, the C-LOT-R has been shown to be a valid measure of optimism [32].

### Data analyses

Sociodemographic and clinical characteristics were descriptively summarized. Mean B-IPQ scores were compared by cancer type using one-way ANOVA. Tukey's test compared the all-pairwise differences between subgroups because it is considered robust when subgroup sample sizes are unequal [33]. Pearson's correlation evaluated the relationships among the eight B-IPQ dimensions. Univariate analysis explored factors associated with different B-IPQ domains with significant factors included in stepwise multiple regression with $p$ values (entry)=0.05 and (removal)=0.1 to adjust for varying sample characteristics. Despite being a non-randomized sample, consecutive sampling, given a large enough sample size, can approximate to the general population and give comparable representativeness to a randomized sample. All data analyses were conducted using Statistical Package for Social Sciences version 20.0 (SPSS, Chicago, IL, USA).

## Results

### Sample characteristics

We approached a consecutive series of 1494 cancer survivors between September 2010 and July 2013. Of these, two died before the study began, 289 were deemed ineligible, and 167 refused to fill out the questionnaire. The resulting 1036 participants represent a response rate of 86.1 %.

Mean participant age was 55.18 years (SD=11.89, range 18–88). Most participants (74.4 %) were married, 66.6 % had secondary or above education attainment, and 64.1 % were currently unemployed. The average duration between the date of the first diagnosis and interview was 10.61 months (SD=11.44); 68.6 % of the participants had previous surgery, 68.8 % chemotherapy, and 79.2 % radiation therapy (Table 1).

### Illness perceptions by cancer type (Table 2)

#### *Consequences*

Mean consequence domain scores varied by cancer type ($F[6, 1006]=6.29$, $p<0.01$). Tukey HSD revealed that nasopharyngeal cancer (NPC) survivors perceived more serious illness effects ($M=5.83$, SD=2.40) than did those diagnosed with other cancer types ($p<0.05$), excepting gynecological cancer survivors ($p>0.05$), who reported more severe effects than did prostate cancer survivors ($p<0.05$).

#### *Timeline*

Of the 1036 cancer survivors, 111 (10.7 %) were unsure of their probable illness duration. These patients were older, had lower education levels, perceived less personal control over and understanding of their illness (all $p<0.05$) (data not shown). Timeline belief did not differ by cancer type ($F[6, 895]=1.78$, $p>0.05$).

#### *Identity*

Mean symptom identity domain scores differed by cancer type ($F[6, 989]=5.87$, $p<0.01$). NPC survivors reported more symptoms ($M=5.65$, SD=2.76) than did those diagnosed with other cancer types ($p<0.05$), excepting lung cancer ($p>0.05$).

#### *Concern*

Mean illness concern domain scores varied by cancer type ($F[6, 998]=3.48$, $p<0.01$). NPC survivors reported more illness concerns ($M=4.71$, SD=2.98) than did prostate cancer survivors ($p<0.05$).

#### *Emotional representation*

Mean emotional representation domain scores also varied by cancer type ($F[6, 998]=3.97$, $p<0.01$). Prostate cancer survivors reported less emotional impact ($M=3.21$, $SD=2.90$) from their disease than did breast, NPC, and gynecological cancer

**Table 1** Sociodemographic and clinical characteristics of the participants

| Variables | *n*=1036 |
|---|---|
| Age (years) | |
| Mean (SD) | 55.18 (11.89) |
| Range | 18–88 |
| Missing | 3 (0.3 %) |
| Gender | |
| Male | 415 (40.1 %) |
| Female | 621 (59.9 %) |
| Marital status | |
| Single | 115 (11.1 %) |
| Married | 771 (74.4 %) |
| Divorced | 82 (7.9 %) |
| Widowed | 65 (6.3 %) |
| Missing | 3 (0.3 %) |
| Education level | |
| No formal | 53 (5.1 %) |
| Primary | 293 (28.3 %) |
| Secondary | 543 (52.4 %) |
| Tertiary | 145 (14.0 %) |
| Missing | 2 (0.2 %) |
| Occupation | |
| Employed | 372 (35.9 %) |
| Retired | 263 (25.4 %) |
| Housewife | 122 (11.8 %) |
| Unemployed | 277 (26.7 %) |
| Missing | 2 (0.2 %) |
| Monthly family income (HK$) | |
| ≤10,000 | 313 (30.2 %) |
| 10,001–20,000 | 294 (28.4 %) |
| 20,001–30,000 | 145 (14.0 %) |
| >30,000 | 223 (21.5 %) |
| Missing | 61 (5.9 %) |
| Cancer type | |
| Breast | 365 (35.2 %) |
| Colorectal | 132 (12.7 %) |
| Nasopharyngeal (NPC) | 158 (15.3 %) |
| Lung | 65 (6.3 %) |
| Gynecological | 113 (10.9 %) |
| Prostate | 74 (7.1 %) |
| Others[a] | 129 (12.4 %) |
| Time since initial diagnosis (months) | |
| Mean (SD) | 10.61 (11.44) |
| Median | 9 |
| Range | 1–145 |
| Missing | 12 (1.2 %) |
| Diagnosed with other cancer | |
| No | 978 (94.4 %) |
| Yes | 55 (5.3 %) |
| Missing | 3 (0.3 %) |

**Table 1** (continued)

| Variables | $n$=1036 |
|---|---|
| Had previous surgery | |
| No | 322 (31.1 %) |
| Yes | 711 (68.6 %) |
| Missing | 3 (0.3 %) |
| Had previous chemotherapy | |
| No | 320 (30.9 %) |
| Yes | 713 (68. 8 %) |
| Missing | 3 (0.3 %) |
| Had previous radiation therapy | |
| No | 212 (20.5 %) |
| Yes | 821 (79.2 %) |
| Missing | 3 (0.3 %) |
| Currently receiving treatment | |
| No | 743 (71.7 %) |
| Yes | 290 (28.0 %) |
| Missing | 3 (0.3 %) |
| Currently taking Chinese medicine | |
| No | 600 (57.9 %) |
| Yes | 433 (41.8 %) |
| Missing | 3 (0.3 %) |
| Family members also had cancer | |
| No | 588 (56.8 %) |
| Yes | 436 (42.1 %) |
| Missing | 12 (1.2 %) |

[a] Cancers with fewer than 20 per group (i.e., stomach, 16 patients; lymphatic, 14 patients; head and neck (tonsils, tongue, salivary gland, vocal cord cancer), 15 patients; thyroid, 6 patients; etc.)

survivors ($p<0.05$) while colorectal cancer (CRC) survivors perceived less emotional impact ($M$=3.54, SD=2.76) than did breast and NPC cancer survivors ($p<0.05$). However, there were no significant difference between prostate and CRC survivors on this dimension ($p>0.05$).

### *Control belief and coherence belief*

Mean score of personal control ($F[6, 981]=0.44$, $p>0.05$), treatment control ($F[6, 981]=1.84$, $p>0.05$), and coherence domains did not differ by cancer type ($F[6, 997]=0.66$, $p>0.05$).

### *Causal belief (Table 3)*

Qualitative data from causal belief open questions was analyzed independently. Overall, 27.4 % of breast, 34.8 % of CRC, 30.4 % of NPC, 27.7 % of lung, 36.3 % of gynecological, 60.8 % of prostate, and 44.2 % of other cancer survivors did not report any known cause for their illness. These respondents were older, with lower education attainment, and less illness coherence, compared to those providing causal attributions (all $p<0.05$) (data not shown). Among those patients holding causal attributions for their cancer, most reported multiple attributions. Among breast cancer survivors, the most frequently reported causal attributions were stress-related (17.3 %), psychological/personality (17.0 %), and life style (12.3 %) factors; for colorectal, NPC, lung, and prostate cancer survivors, lifestyle, environment, and health-related factors were the three leading causal attributions cited. Gynecological cancer survivors were more likely to identify stress-related (15.9 %), health-related (11.5 %), and environment factors (10.6 %). Among other cancer survivors, lifestyle (27.9 %), environment (8.5 %), and psychological/personality (6.2 %) factors were most frequently cited.

**Table 2** B-IPQ mean score (±SD) by cancer type

| | Breast cancer ($n$=365) | Colorectal cancer ($n$=132) | NPC ($n$=158) | Lung cancer ($n$=65) | Gynecological cancer ($n$=113) | Prostate cancer ($n$=74) | Others ($n$=129) | $p$ value |
|---|---|---|---|---|---|---|---|---|
| Consequences | 4.70 (2.63) | 4.43 (2.76) | 5.83 (2.40) | 4.62 (2.71) | 5.12 (2.64) | 3.82 (2.76) | 4.91 (2.94) | <0.001 |
| Timeline | 4.92 (3.24) | 4.42 (2.97) | 4.86 (3.04) | 5.58 (3.12) | 4.52 (2.58) | 4.15 (3.15) | 4.41 (3.07) | 0.101 |
| Personal control[a] | 5.26 (3.01) | 5.28 (3.07) | 5.41 (2.97) | 4.89 (3.06) | 5.47 (3.08) | 5.21 (3.24) | 5.00 (3.44) | 0.852 |
| Treatment control[a] | 7.86 (1.82) | 8.05 (2.12) | 8.40 (1.85) | 7.75 (2.20) | 8.19 (2.07) | 8.11 (2.07) | 7.87 (2.00) | 0.088 |
| Identity | 4.64 (2.86) | 3.90 (2.46) | 5.65 (2.76) | 4.40 (2.95) | 4.51 (2.86) | 3.83 (2.99) | 4.31 (3.17) | <0.001 |
| Concern | 4.53 (2.87) | 3.79 (2.95) | 4.71 (2.98) | 3.65 (2.98) | 4.54 (3.06) | 3.40 (2.74) | 3.91 (3.33) | 0.002 |
| Coherence[b] | 6.07 (2.45) | 6.02 (2.94) | 5.75 (2.92) | 5.43 (3.03) | 6.00 (2.81) | 5.85 (2.73) | 6.02 (3.04) | 0.679 |
| Emotional representation | 4.48 (2.81) | 3.54 (2.76) | 4.57 (2.89) | 3.97 (2.77) | 4.58 (2.62) | 3.21 (2.91) | 4.14 (3.20) | 0.001 |

*B-IPQ* Brief Illness Questionnaire, score range of B-IPQ domains: 0–10

[a] Higher score means more perceived control

[b] Higher score means more understanding of the illness

**Table 3** The percentage of perceived leading cause and total number of cause by cancer type ($n$=1036)

| | Breast cancer ($n$=365) % | Colorectal cancer ($n$=132) % | NPC ($n$=158) % | Lung cancer ($n$=65) % | Gynecological cancer ($n$=113) % | Prostate cancer ($n$=74) % | Others ($n$=129) % |
|---|---|---|---|---|---|---|---|
| Do not know | 27.4 | 34.8 | 30.4 | 27.7 | 36.3 | 60.8 | 44.2 |
| Stress-related | 17.3 | 2.3 | 7.0 | 4.6 | 15.9 | 0.0 | 3.9 |
| Environment | 8.8 | 15.9 | 17.7 | 13.8 | 10.6 | 8.1 | 8.5 |
| Psychological/personality | 17.0 | 3.0 | 5.1 | 4.6 | 8.8 | 5.4 | 6.2 |
| Health-related | 4.9 | 8.3 | 8.9 | 7.7 | 11.5 | 12.2 | 5.4 |
| Genetic/heredity | 6.8 | 5.3 | 7.6 | 1.5 | 7.1 | 4.1 | 1.6 |
| Hormone/related | 5.2 | 0.0 | 0.0 | 0.0 | 1.8 | 0.0 | 0.0 |
| Fatalistic belief | 0.3 | 0.0 | 1.9 | 0.0 | 0.0 | 0.0 | 1.6 |
| Perceived one cause | 18.6 | 28.0 | 20.3 | 30.8 | 15.0 | 23.0 | 19.4 |
| Perceived two causes | 24.7 | 21.2 | 20.9 | 32.3 | 21.2 | 10.8 | 20.2 |
| Perceived three causes | 29.3 | 15.9 | 28.5 | 9.2 | 27.4 | 5.4 | 16.3 |

Health-related factors included previous illness, body weakness, previous medication, pervious operation, etc., reported by the patients

### Relationships between B-IPQ domains, physical symptom distress, and optimism (Table 4)

The symptom identity domain was not significantly correlated with personal control. The coherence domain was not significantly related to the consequences, concern, and emotional representation domains. Otherwise, domains were significantly correlated with each other ($p<0.01$). Personal and treatment control domains were negatively related to the other six domains ($p<0.01$), which were otherwise positively correlated with each other ($p<0.01$). Physical symptom distress was significantly associated with all illness perception domains ($p<0.05$), excepting perceived treatment control. Optimism was significantly related to all illness perception domains (all $p<0.01$).

### Multivariate analyses (Table 5)

Stepwise multiple regression analyses adjusted illness perception domain associations for cancer type, sample differences in demographic (gender, age, education level, occupation, family income level) and clinical characteristics (cancer type, time since initial diagnosis, treatment type, current treatment, family history) and examined physical symptom distress and dispositional optimism.

Physical symptom distress remained significantly associated with all illness perception domains, excepting personal and treatment control beliefs (both $p>0.05$). Higher physical symptom distress was associated with higher perceived illness impacts ($\beta$=0.340, $p<0.01$), longer disease duration ($\beta$=0.143, $p<0.01$), more serious symptoms ($\beta$=0.296, $p<0.01$),

**Table 4** B-IPQ correlation matrix

| | Mean (SD) | Consequences | Timeline | Personal control | Treatment control | Identity | Concern | Coherence | Emotional representation |
|---|---|---|---|---|---|---|---|---|---|
| Consequences | 4.84 (2.71) | 1 | | | | | | | |
| Timeline | 4.73 (3.08) | 0.358** | 1 | | | | | | |
| Personal control | 4.75 (3.09) | −0.084** | −0.283** | 1 | | | | | |
| Treatment control | 1.98 (1.96) | −0.117** | −0.258** | 0.285** | 1 | | | | |
| Identity | 4.58 (2.90) | 0.369** | 0.259** | −0.039 | −0.112** | 1 | | | |
| Concern | 4.25 (3.00) | 0.477** | 0.336** | −0.096** | −0.111** | 0.357** | 1 | | |
| Coherence | 4.94 (2.76) | −0.054 | −0.089** | 0.279** | 0.167** | 0.117** | 0.008 | 1 | |
| Emotional representation | 4.22 (2.88) | 0.554** | 0.323** | −0.103** | −0.126** | 0.391** | 0.685** | 0.037 | 1 |
| Physical symptom distress | 0.48 (0.53) | 0.399** | 0.195** | −0.078* | −0.057 | 0.319** | 0.285** | −0.082** | 0.392** |
| Dispositional optimism | 16.78 (2.75) | −0.210** | −0.257** | 0.216** | 0.187** | −0.153** | −0.245** | 0.153** | −0.296** |

*B-IPQ* Brief Illness Perception Questionnaire

*$p<0.05$; **$p<0.01$

**Table 5** Multiple regression of factors associated with B-IPQ domains

| | Consequences | Timeline | Personal control | Treatment control | Identity | Concern | Coherence | Emotional representation |
|---|---|---|---|---|---|---|---|---|
| Age | −0.148** | – | −0.069* | – | – | −0.158** | −0.097** | −0.149** |
| Gender | | | | | | | | |
| Male | Referent | Referent | Referent | Referent | Referent | Referent | Referent | Referent |
| Female | – | – | – | – | – | 0.123** | – | 0.129** |
| Education level | | | | | | | | |
| Primary or below | Referent | Referent | Referent | Referent | Referent | Referent | Referent | Referent |
| Secondary or above | – | – | 0.077* | – | – | – | 0.187** | – |
| Occupation | | | | | | | | |
| Employed | Referent | Referent | Referent | Referent | Referent | Referent | Referent | Referent |
| Not employed | 0.106** | | | | 0.070* | 0.087** | | 0.087** |
| Total monthly household income (HK$) | | | | | | | | |
| Below 10,000 | Referent | Referent | Referent | Referent | Referent | Referent | Referent | Referent |
| 10,001–20,000 | – | – | – | – | – | – | – | – |
| 20,001–30,000 | – | – | – | – | – | – | – | – |
| More than 30,000 | – | – | – | – | – | – | – | – |
| Cancer type | | | | | | | | |
| Colorectal | Referent | Referent | Referent | Referent | Referent | Referent | Referent | Referent |
| Breast | – | – | – | – | – | – | – | – |
| NPC | – | – | – | – | – | – | – | – |
| Lung | – | – | – | – | – | – | – | – |
| Gynecological | – | – | – | – | – | – | – | – |
| Prostate | – | – | – | – | – | – | – | – |
| Others | – | – | – | – | – | – | – | – |
| Time since first diagnosis | – | – | −0.068* | – | – | – | – | – |
| Surgery | – | – | – | – | – | – | – | – |
| Chemotherapy | – | – | – | – | 0.150** | – | – | – |
| Taking Chinese medicine now | 0.062* | – | – | – | 0.063* | 0.080** | – | 0.107** |
| Physical symptom distress | 0.340** | 0.143** | – | – | 0.296** | 0.215** | −0.096** | 0.318** |
| Optimism | −0.137** | −0.225** | 0.218** | 0.187** | −0.096* | −0.198** | 0.121** | −0.228** |
| $R^2$ | *0.198* | *0.085* | *0.061* | *0.035* | *0.136* | *0.171* | *0.084* | *0.261* |

The italic values are $R^2$

Variables were excluded and retained with $p$ values (entry)=0.05 and (removal)=0.1

*B-IPQ* Brief Illness Questionnaire

*$p<0.05$; **$p<0.01$

greater illness concern ($\beta=0.215$, $p<0.01$), and perceived emotional impact ($\beta=0.318$, $p<0.01$), but less disease understanding ($\beta=-0.096$, $p<0.01$).

Dispositional optimism was negatively associated with consequence ($\beta=-0.137$, $p<0.01$), timeline ($\beta=-0.225$, $p<0.01$), identity ($\beta=-0.096$, $p<0.01$), concern ($\beta=-0.198$, $p<0.01$), and emotional impact ($\beta=-0.228$, $p<0.01$) domains, but positively correlated with personal control ($\beta=0.218$, $p<0.01$), treatment control ($\beta=0.187$, $p<0.01$), and coherence ($\beta=0.121$, $p<0.01$) domains.

Younger cancer survivors reported more severe consequences ($\beta=-0.148$, $p<0.01$), personal control ($\beta=-0.069$, $p<0.05$), illness concerns ($\beta=-0.158$, $p<0.01$), illness understanding ($\beta=-0.097$, $p<0.01$), and emotional impact ($\beta=-0.149$, $p<0.01$). Females had more concerns ($\beta=0.123$, $p<0.01$) and emotional impacts ($\beta=0.129$, $p<0.01$) than did males. Better-educated respondents reported more personal control ($\beta=0.077$, $p<0.01$) and better illness understanding ($\beta=0.187$, $p<0.01$). Unemployed respondents reported more serious illness effects ($\beta=0.106$, $p<0.01$), more serious symptoms ($\beta=-0.070$, $p<0.05$), concerns ($\beta=0.087$, $p<0.01$), and emotional impacts ($\beta=0.087$, $p<0.01$) than did employed respondents. After controlling for potential confounders in the regression model, cancer type was not correlated with any of illness perception domains ($p>0.05$). Cancer survivors who had chemotherapy ($\beta=0.150$, $p<0.01$) experienced more symptoms.

## Discussion

Three key findings emerge from this study of six groups of cancer survivors. First, patients with different cancer types initially differed in illness perceptions. However, after adjusting for other demographic, clinical, and psychometric variables, no significant differences in illness perceptions by cancer types remained. While refuting our null hypothesis, this is more plausible. Illness perceptions instead showed significant variation by age, gender, education level, employment status, optimism, and physical symptom distress, suggesting that the apparent variance in illness perceptions among survivors of different cancer types is attributable to individual differences in age, gender, education level, employment status, treatment type, physical symptom distress, and optimism. Either all cancer types are seen as one "global" disease ("cancer") by different people or more likely it is not the disease per se, but the impacts on daily life that are pertinent to patients and reactions to those impacts vary by individual characteristics. Emotional rather than cognitive elements of illness representations were emphasized and were strongly age and gender patterned. Otherwise, the magnitude and directions of observed inter-correlations between IPQ domains were consistent with previous studies [34, 35].

Younger survivors reported more serious illness effects and greater emotional impacts than did older survivors. Yet, younger survivors also perceived more personal control and had greater understanding of their disease and illness concerns. Elsewhere, younger age was associated with more symptoms, anxiety, and depression in breast cancer survivors [36] while younger CRC patients report more unmet needs than did their older counterparts [37]. Though our older cancer survivors less often received chemotherapy (data not shown), being less likely to experience chemotherapy-related symptoms, among those that do, older patients report fewer impacts on life [38]. Conversely, younger survivors more likely have higher educational achievement, conferring easier online and other health-related information access, and greater proactivity in communicating with health professionals, thereby understanding cancer better. Female cancer survivors reported more illness concerns and emotional impacts than did males. Women generally appear more health-oriented and emotionally expressive than men [39]. Many cancer survivors considered returning to work as a significant marker of renormalization and anticipate improved quality of life [40]. Younger people aged 30–65 usually have more roles than older retired patients including work, breadwinning, childminding, maintaining family and home, and looking after elderly relatives. Cancer and its treatments impair roles performance in all patients, but younger patients may experience greater frustration and distress at "premature" restrictions usually associated with older age. We found that unemployed cancer survivors perceived more disease consequences and had more concerns and emotional representations than those who were employed. Hence, people experiencing greater impacts may be less likely to return to work, accounting for higher reported illness perceptions in the unemployed.

Patients reporting more severe symptoms also perceived a longer illness, duration, more severe consequences, illness concerns and emotional impacts, and less treatment control and disease understanding. Those having had chemotherapy reported more symptom identity. Among the 713 (68.0 %) survivors who had received chemotherapy, most (99.6 %) also had surgery and/or radiation therapy. Post hoc analysis revealed that these patients reported more symptoms including lack of energy, dry mouth, loss of appetite, and change of food taste (data not shown). Similarly, a study of Dutch cancer patients indicated that people having treatments other than surgery were more likely to report that their illness seriously affected their lives [26].

Second, physical symptom distress was significantly associated with illness perceptions, excepting the control beliefs domain. Folkman suggested that believing an event is controllable is not always associated with changes of the level of stress or outcomes [41]. Greater physical symptom distress was associated with more negative illness perceptions, suggesting that physical symptom-related distress becomes a component of symptom experience and thereby illness perceptions [11, 12], or that more negative illness perceptions elicit greater intolerance and/or reporting of distress. Independently, dispositional optimism was significantly and positively correlated with all the illness perception domains among these Chinese cancer survivors. Optimists have more positive expectancies of future outcomes [18]; thus, optimistic patients are more likely to have more positive representation of their illness, given an optimistic tendency is more likely to pre-date cancer than vice versa.

Third, for most of these cancers, the underlying causes remain unclear. Many cancer survivors did not offer a reason for their cancer. Perhaps these respondents had fatalistically not dwelled on the causes, or lacked awareness of risk factors. These were more often older, lower educated people reporting less illness understanding. Those attributing a reason for developing cancer gave several reasons, though most lack scientific evidence.

Breast and gynecological cancer survivors more frequently attributed their disease to psychological causes: stress-related, psychological/personality, and lifestyle factors. Female Asian patients seem to more often attribute disease to psychological causes. Studies of Anglophone populations reported family history/genetics, environmental factors, and then stress were the most frequently reported causal attributions [42]. American gynecological cancer survivors most frequently reported genetics/heredity, stress, and God's will as causal [43]. These findings reflect different scientific emphasis and cultural influence between the samples. Genetics is heavily emphasized in North America, which has a higher BRCA1 & 2 awareness, whereas Hong Kong's stressful lifestyle represents an accessible, but scientifically unsubstantiated, cause of cancer. CRC, NPC, lung, and prostate cancer survivors attributed cause to lifestyle, environment, and health-related factors, consistent with American cancer survivors, who identified lifestyle, biological, and environment factors as the most common causal attributions [44] and scientific evidence. Other Hong Kong Chinese cancer survivors identified combinations of life style, environment, and psychological/personality factors. Causal attributions influence illness adjustment [45]. Factors such as stress, genetics/biological/health, environment, and God's will reflect external factors that place the survivor in the role of victim of forces beyond their control, avoiding culpability and guilt. Lifestyle factors are more controllable and point to subsequent lifestyle changes to minimize recurrence. This might not be expected for the former attributions.

This study examined illness representations in over 1000 adult Chinese cancer survivors, enhancing theoretical insights of how survivors construe their illness and how physical symptom distress and dispositional optimism relate thereto. Study limitations include cross-sectional nature, low representation of rarer cancer types, and slight sample-population discrepancy. Only the largest and truly random samples generalize readily to the wider population. Our large sample size and geographically broad and long duration of recruitment are important strengths.

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**Compliance with ethical standards** Ethical approval was granted by The University of Hong Kong and public Hospital Authority ethics committees. All procedures performed in studies involving human participants were in accordance with the ethical standards of the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed consent** Informed consent was obtained from all participants included in the study.

**Conflict of interest** The authors declare that they have no competing interests.

## References

1. Overview of 2012 Hong Kong cancer statistics (2014) Hong Kong
2. Sanchez-Jimenez A, Cantarero-Villanueva I, Delgado-Garcia G, Molina-Barea R, Fernandez-Lao C, Galiano-Castillo N, Arroyo-Morales M (2014) Physical impairments and quality of life of colorectal cancer survivors: a case–control study. Eur J Cancer Care. doi:10.1111/ecc.12218
3. Davis KM, Kelly SP, Luta G, Tomko C, Miller AB, Taylor KL (2014) The association of long-term treatment-related side effects with cancer-specific and general quality of life among prostate cancer survivors. Urology 84(2):300–306. doi:10.1016/j.urology.2014.04.036
4. Schmitz KH, Speck RM, Rye SA, DiSipio T, Hayes SC (2012) Prevalence of breast cancer treatment sequelae over 6 years of follow-up: the pulling through study. Am Cancer Soc 118(8 Suppl):2217–2225. doi:10.1002/cncr.27474
5. Leventhal H, Meyer D, Nerenz D (1980) The common sense representation of illness danger. In: Rachman S (ed) Medical psychology, vol 2. Pergamon Press, New York, pp 7–30
6. Leventhal H, Steele D (1984) Illness representations and coping with health threats. In: Rachman S (ed) Handbook of psychology and health, vol 4. Erlbaum, Hillside, pp 219–252
7. Holly R, Paula W (2013) Illness cognitions and perceptions. Encyclopedia of behavioral medicine. 1027–1030. doi:10.1007/978-1-4419-1005-9_967
8. Nerenz D, Leventhal H (1983) Self-regulation theory in chronic illness. In: Burish T, Bradley L (eds) Coping with chronic disease. Research and applications. Academic, New York, pp 13–37
9. Armstrong TS (2003) Symptoms experience: a concept analysis. Oncol Nurs Forum 30(4):601–606. doi:10.1188/03.ONF.601-606
10. Leventhal H, Brissette I, Leventhal E (2003) The common-sense model of self-regulation of health and illness. In: Cameron L, Leventhal H (eds) The self-regulation of health and illness behaviour. Routledge, UK, pp 42–65
11. Wong WS, Fielding R (2013) Suppression of emotion expression mediates the effects of negative affect on pain catastrophizing: a cross-sectional analysis. Clin J Pain 29(10):865–872. doi:10.1097/AJP.0b013e31827da3b5
12. Wong WS, Lam HM, Chen PP, Chow YF, Wong S, Lim HS, Jensen MP, Fielding R (2015) The fear-avoidance model of chronic pain: assessing the role of neuroticism and negative affect in pain catastrophizing using structural equation modeling. Int J Behav Med 22(1):118–131. doi:10.1007/s12529-014-9413-7
13. McAndrew L, Mora P, Quigley K, Leventhal E, Leventhal H (2014) Using the common sense model of self-regulation to understand the relationship between symptom reporting and trait negative affect. Int J Behav Med 21(6):989–994. doi:10.1007/s12529-013-9372-4
14. Thune-Boyle ICV, Myers LB, Newman SP (2006) The role of illness beliefs, treatment beliefs, and perceived severity of symptoms in explaining distress in cancer patients during chemotherapy treatment. Behav Med 32(1):19–29
15. Lam WWT, Li WWY, Bonanno GA, Mancini AD, Chan M, Or A, Fielding R (2012) Trajectories of body image and sexuality during the first year following diagnosis of breast cancer and their relationship to 6 years psychosocial outcomes. Breast Cancer Res Treat 131(3):957–967
16. Lam WWT, Soong I, Yau TK, Wong KY, Tsang J, Yeo W, Suen J, Ho WM, Sze WK, Ng AWY, Kwong A, Suen D, Fielding R (2013) The evolution of psychological distress trajectories in women diagnosed with advanced breast cancer: a longitudinal study. Psycho-Oncology 22(12):2831–2839
17. Lam WWT, Ye M, Fielding R (2012) Trajectories of quality of life among Chinese patients diagnosed with nasopharyngeal cancer. PloS One 7(9):e44022. doi:10.1371/journal.pone.0044022
18. Carver CS, Scheier MF (2014) Dispositional optimism. Trends Cogn Sci 18(6):293–299
19. Hurt C, Burn D, Hindle J, Samuel M, Wilson K, Brown R (2014) Thinking positively about chronic illness: an exploration of optimism, illness perceptions and well-being in patients with Parkinson's disease. Br J Health Psychol 19(2):363–379

20. Vollmann M, Scharloo M, Langguth B, Kalkouskaya N, Salewski C (2014) Illness representations as mediators of the relationship between dispositional optimism and depression in patients with chronic tinnitus: a cross-sectional study. Psychol Health 29(1):81–93. doi:10.1080/08870446.2013.828294
21. Henselmans I, Sanderman R, Helgeson VS, de Vries J, Smink A, Ranchor AV (2010) Personal control over the cure of breast cancer: adaptiveness, underlying beliefs and correlates. Psycho-Oncology 19(5):525–534
22. Zenger M, Brix C, Borowski J, Stolzenburg JU, Hinz A (2010) The impact of optimism on anxiety, depression and quality of life in urogenital cancer patients. Psycho-Oncology 19(8):879–886
23. Gray NM, Hall SJ, Browne S, Johnston M, Lee AJ, Macleod U, Mitchell ED, Samuel L, Campbell NC (2014) Predictors of anxiety and depression in people with colorectal cancer. Support Care Cancer 22(2):307–314
24. Mickeviciene A, Vanagas G, Jievaltas M, Ulys A (2013) Does illness perception explain quality of life of patients with prostate cancer? Med Lith 49(5):235–241
25. Husson O, Thong MSY, Mols F, Oerlemans S, Kaptein AA, van de Poll-Franse LV (2013) Illness perceptions in cancer survivors: what is the role of information provision? Psycho-Oncology 22(3):490–498
26. Hopman P, Rijken M (2015) Illness perceptions of cancer patients: relationships with illness characteristics and coping. Psycho-Oncology 24(1):11–18
27. Broadbent E, Petrie KJ, Main J, Weinman J (2006) The brief illness perception questionnaire. J Psychosom Res 60(6):631–637
28. Xue F, Lin Y Brief illness perception questionnaire: Chinese version. http://www.uib.no/ipq/pdf/B-IPQ-Chinese.pdf. Accessed on 01 Aug 2010
29. Fan SY, Eiser C, Ho MC, Lin CY (2013) Health-related quality of life in patients with hepatocellular carcinoma: the mediation effects of illness perceptions and coping. Psycho-Oncology 22(6):1353–1360
30. Schaefert R, Honer C, Salm F, Wirsching M, Leonhart R, Yang JZ, Wei J, Lu W, Larisch A, Fritzsche K (2013) Psychological and behavioral variables associated with the somatic symptom severity of general hospital outpatients in China. Gen Hosp Psychiatry 35(3):297–303
31. Lam WWT, Law CC, Fu YT, Wong KH, Chang VT, Fielding R (2008) New insights in symptom assessment: the Chinese versions of the Memorial Symptom Assessment Scale Short Form (MSAS-SF) and the Condensed MSAS (CMSAS). J Pain Symptom Manag 36(6):584–595
32. Lai J, Yue X (2000) Measuring optimism in Hong Kong and mainland Chinese with the revised life orientation test. Personal Individ Differ 28(4):781–796. doi:10.1016/S0191-8869(99)00138-5
33. McHugh ML (2011) Multiple comparison analysis testing in ANOVA. Biochem Med 21(3):203–209
34. Yan J, You LM, He JG, Wang JF, Chen L, Liu BL, Zhou JJ, Chen JH, Jin SY (2011) Illness perception among Chinese patients with acute myocardial infarction. Patient Educ Couns 85(3):398–405
35. Hagger M, Orbell S (2003) A meta-analytic review of the common-sense model of illness representations. Psychol Health 18(2):141–184. doi:10.1080/088704403100081321
36. Kertmen N, Sahin U, Keskin O, Solak M, Petekkaya I, Babacan T, Sarici F, Arik Z, Kizilarslanoglu B, Altundag K (2012) Comparison of clinicopathological characteristics and outcome of younger and older breast cancer patients. J BUON 17(4):797
37. Fielding R, Lam WWT, Shun SC, Okuyama T, Lai YH, Wada M, Akechi T, Li WWY, Appon (2013) Attributing variance in supportive care needs during cancer: culture-service, and individual differences, before clinical factors. PloS One 8(5):e65099. doi:10.1371/journal.pone.0065099
38. Blank TO, Bellizzi KM (2008) A gerontologic perspective on cancer and aging. Am Cancer Soc 112(11):2569–2576
39. Verbrugge LM (1985) Gender and health: an update on hypotheses and evidence. J Health Soc Behav 26(3):156–182
40. Stergiou-Kita M, Grigorovich A, Tseung V, Milosevic E, Hebert D, Phan S, Jones J (2014) Qualitative meta-synthesis of survivors' work experiences and the development of strategies to facilitate return to work. J Cancer Surviv 8(4):657–670
41. Folkman S (1984) Personal control and stress and coping processes: a theoretical analysis. J Pers Soc Psychol 46(4):839–852
42. Dumalaon-Canaria JA, Hutchinson AD, Prichard I, Wilson C (2014) What causes breast cancer? A systematic review of causal attributions among breast cancer survivors and how these compare to expert-endorsed risk factors. Cancer Causes Control 25(7):771–785
43. Costanzo ES, Lutgendorf SK, Bradley SL, Rose SL, Anderson B (2005) Cancer attributions, distress, and health practices among gynecologic cancer survivors. Psychosom Med 67(6):972–980
44. Ferrucci LM, Cartmel B, Turkman YE, Murphy ME, Smith T, Stein KD, McCorkle R (2011) Causal attribution among cancer survivors of the 10 most common cancers. J Psychosoc Oncol 29(2):121–140. doi:10.1080/07347332.2010.548445
45. Oba S, Takatsuka N, Nagata C, Nagao Y, Yamamoto S, Shibuya C, Kashiki Y, Shimizu H (2009) Causal attributions to epidemiological risk factors and their associations to later psychological adjustment among Japanese breast cancer patients. Support Care Cancer 17(1):3–9