Distress and quality of life: An exploratory study of Chinese-speaking cancer patients and family caregivers in Canada

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Conflict of Interest: The authors have no conflicts of interest to disclose.

December 23, 2018

Abstract

Objective: This study explores the relationships of patient distress, family caregiver distress and patient quality of life (QOL) in a Chinese-speaking cancer population, using a comparison group of Anglophone patients and family caregivers in British Columbia, Canada.

Methods: Quantitative regression analysis of survey data was conducted to examine the direct and indirect effects of patient and family caregiver distress on patient QOL based on data from 29 Chinese-speaking and 28 Anglophone dyads. Semi-structured interviews were conducted with a purposive sample of ten Chinese-speaking patients and six family caregivers to further clarify the interrelationships among patient distress, family caregiver distress and patient QOL.

Results: Patient distress was a significant predictor of patient QOL ($\beta = -.79$). The effects of patient age on patient emotional well-being were mediated by patient distress, such that lower distress in older patients explained better emotional functioning. A key theme from the qualitative data analysis was the emotional regulation of patient and family caregiver, where both sought to regulate their emotions to protect each other from further cancer-related distress.

Conclusion: These results highlight the importance of understanding the patients' and family members' cultural and social context, in patient- and family-centred care.

1 INTRODUCTION

Cancer is a family disease, affecting not only individual patients, but also having a substantial impact on the family (Kim & Given, 2008; Northouse, 2005). Distress experienced by a family member has a significant impact on other members, affecting patients' and the family members' adaptation to changes brought on by cancer, and subsequently their quality of life (QOL) (Northouse, Mellon, Harden, & Schafenacker, 2009). Kim and Given (2008) assert that a person's QOL is influenced by the availability of resources to the individual – including sociodemographic, medical, psychosocial, and physical health factors (Kim & Given, 2008). It follows that it is paramount to recognize and address the multidimensional effects of cancer on patients as well as on family members who assume the role of upholding the ill person's QOL through caregiving.

Although many issues related to cancer may be universal, ramifications of problems that patients and their families face are magnified or mitigated by their social and cultural environments (Ho, Saltel, Machavoine, Rapoport-Hubschman, & Spiegel, 2004). Social comprises the relationships in community, and culture constitutes a fluid and dynamic process that changes over time (Almutairi, Dahinten, & Rodney, 2015). As the impact of cancer on the family is embedded in the cultural and social contexts in which the patients and the family caregivers are situated, it is important to understand the cultural context of behaviours involved in both seeking and providing care (Lee, 2007).

At present, there is a dearth of research on the experiences of cancer in people with culturally and linguistically diverse backgrounds (Given, Sherwood, & Given, 2011; Stenberg, Ruland, & Miaskowski, 2010). With over 16% of the Canadian population identified as ethnic minorities, and 15% of Greater Vancouver population in British Columbia (BC) indicating Chinese as their mother tongue, the need for culturally appropriate care for Chinese cancer patients and families is evident. For Chinese-speaking patients and their families, adjusting to cancer may be particularly distressing when culture and

language are not congruent with the mainstream model of care delivery. Where death and dying is a taboo topic, members in the Chinese family may be reluctant to discuss the disease, especially in the presence of the patient (Lee & Bell, 2011). Coupled with the cultural belief that cancer is "contagious", the impact of social stigma is particularly distressing when such beliefs about cancer are upheld in one's community, further isolating the patient and reducing the social support network (Cheng et al., 2013).

This cross-cultural study explored the relationships between patient distress, family caregiver distress, and patient QOL by comparing Chinese and Anglophone patients and family caregivers in BC. Particularly, the direct and indirect effects of patient and family caregiver distress on patient QOL, and the interrelationships among patient distress, family caregiver distress and patient QOL, were investigated. The conceptual framework of this study was adapted from Northouse's and colleagues' stress-appraisal model that described important theoretical relationships between stress and patient and family caregiver QOL of (Northouse et al., 2002). In this study framework (Figure 1), patient QOL was influenced by factors related to the patient and family caregiver background (age, sex, education, English fluency, migration history), the illness (cancer site, cancer stage, treatment) and the nature of caregiving (caregiving duration and type of patient-family caregiver dyadic relationship). While these factors may directly impact patient QOL, the factors could also influence patient QOL indirectly through the patient and family caregiver appraisals of their own distress. That is, distress may mediate the effects of these factors on QOL. Further, the level of distress of the patient and the family caregivers may be interrelated, reflecting the reciprocal reaction of the ill person and the family caregiver to cancer as an "emotional system" (Northouse, Katapodi, Schafenacker, & Weiss, 2012, p. 237).

2 METHODS

2.1 Study design

This exploratory study is part of a larger research project. This study used quantitative analysis of cross-sectional surveys and qualitative analysis of semi-structured interviews from a sample of Chinese-speaking and Anglophone-Canadian cancer patients and family caregivers living in Greater Vancouver. The linguistic aspect of culture was used to define the population groups investigated, considering the challenges in operationalizing culture in cross-cultural studies. Regression analysis of survey data was conducted to examine the direct and indirect effects of patient and family caregiver distress on patient QOL. Thematic analysis of interview data was used to draw insights about the structural relationships of patient distress, family caregiver distress and patient QOL. Particularly, the interrelatedness between patient and family caregiver distress, and its impact on patient QOL in Chinese-speaking families was investigated.

2.2 Sampling and data collection

The study's Chinese-speaking patient population included persons who: a) were 19 years or older, b) identified Cantonese or Mandarin as their first language, c) resided in BC, d) were diagnosed with Stage I to III cancer, e) were between 6 months to 2 years post diagnosis, and f) had identified at least one family caregiver. Family caregivers in this study were identified by the patients as those family support persons who were primarily involved in their day-to-day care. A comparison group of Anglophone-Canadian patients and family caregivers was used to provide a backdrop for interpretation of the results for the target group. The Anglophone cancer patient and family caregiver participants represented the broader Canadian society of non-Chinese native English-speakers. With the exception of the language fluency inclusion criteria, the same eligibility conditions applied to the comparison group. The study

protocol was reviewed and approved by the University of British Columbia Behavioural Research Ethics Board and the Vancouver Coastal Health Research Institute.

Questionnaires were administered in person, over the phone or by mail, as per the participants' preference for data collection modality. A total of 55 patients and 40 family caregivers completed the surveys. Among the survey participants, a total of ten Chinese-speaking patients and six family caregivers were also interviewed by the first author. These 16 participants included five patients who participated along with their family caregivers, comprising dyads; five patients who participated but whose family caregivers did not; and one family caregiver who participated without the patient's involvement. Adopting a funnel approach (Emerson, Fretz, & Shaw, 1995), the interviews began with broad questions on the participants' overall experience with cancer, followed by more focused questions on their experience of distress.

2.3 Measures

The English and Chinese versions of the short-form Kessler Psychological Distress Scale (K6) of non-specific psychological distress were used to assess patient distress and caregiver distress, being the key independent variables in relation to patient QOL (Kessler et al., 2003). Consisting of six core questions that centred on non-specific psychological distress, the K6 asks respondents to rate how frequently they experienced symptoms of general anxiety and depression during the past thirty days on a five-point scale (from 1= all of the time to 5 = none of the time) (Kessler et al., 2003). The Chinese version of the instrument has been reported to have good reliability and validity for evaluation of mental health status in the Chinese population in China, with Cronbach alpha reported at 0.8 (Zhou, Chu, & Wang, 2008).

The Functional Assessment of Cancer Therapy-General (FACT-G) scale in English and Chinese was used to measure patient QOL. The FACT-G is a self-report questionnaire that consists of 27 items that measure the following four domains of patient QOL/well-being, as a function of treatment: physical

(7 items), social/family (7 items), emotional (6 items), functional (7 items) (Cella & Tulsky, 1993; Cella et al., 1993). Respondents were asked to rate each item on a five-point scale (from 0 = Not at all to 4 = Very much) based on a recall period of seven days. The items' scores in each domain were summed to construct subscales; the subscales were subsequently summed to obtain a total score measuring overall QOL (referred to as "QOL total" from hereon). The Chinese version of the FACT-G has reported good reliability and validity; Cronbach alpha was reported at 0.85 (Yu et al., 2000).

Additional measures examined in the quantitative analyses include patient and family caregiver characteristics (age, sex, education, years in Canada, English fluency), cancer diagnosis (site, stage, treatment), type of patient-family caregiver relationship, and duration of family caregiving.

2.4 Data analyses

Among the participants who have completed the surveys, there were 38 dyads of patients and their family caregivers; however, participation from both individuals was not always possible, and non-dyadic data consisted of 17 patient participants and 2 family caregiver participants. Following established guidelines, multiple imputation (MI) was performed to impute missing values of all covariates, independent and dependent variables in the study with incomplete data (Graham, 2012; Rombach, Rivero-Arias, Gray, Jenkinson, & Burke, 2016; Young & Johnson, 2013). MI was conducted on distress total scores for the patients and for the family caregivers; QOL total scores were computed after MI of subscale scores. Consistent with experts' recommendations, 10 datasets were imputed in the study (Rubin, 1987). MI of missing values of the 19 individuals with incomplete dyads resulted in data for 29 Chinese-speaking and 28 Anglophone dyads; the percentage of data points imputed was 11.5%. Results were compared with those based on complete case analysis.

Multiple linear regression was used to investigate the direct effects of patient and family caregiver characteristics (patient factors, illness-related factors, social/family factors, and family caregiver factors) and distress on patient QOL. Separate regression analyses were conducted for each

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QOL subscale and QOL total. Prior bivariate regression analyses were conducted to identify statistically significant covariates ($p < .05$) for inclusion in the multivariate regression models. To examine the indirect effects of patient and family caregiver distress levels on patient QOL, mediation analysis was conducted for QOL total and the subscales that had significant associations with distress and with one or more of the patient and family caregiver characteristics, as found in the combined sample of Chinese-speaking and Anglophone groups (MacKinnon, 2008). The SPSS 22 software was used for statistical analysis. A final study sample of 57 observations comprising 29 Chinese-speaking and 28 Anglophone dyads provided sufficient power to detect a large effect size for multiple regression with 10 independent variables, at an alpha level of .05 and power of .8 (Cohen, 1992).

The interrelationships among patient distress, family caregiver distress and patient QOL were further explored in the qualitative analysis (Lee, Gotay, Sawatzky, & Kazanjian, 2018). Adapting Emerson et al.'s (Emerson, Fretz, & Shaw, 1995) approach to analyzing field notes, the initial stage of the qualitative data analysis involved open coding of the 16 sets of interview notes, to identify and formulate the range of themes in the data. As the analysis progressed, focused coding was employed, with notes coded on the basis of emerging topics that were of particular interest. To compare patient and family caregiver responses to issues of distress following a cancer diagnosis, the interview data were also examined within each patient-family caregiver dyad. The information extracted from the dyadic responses was compared with that from the data coded at the individual level; where there was new information, insights drawn from the analysis of the dyadic data were integrated with the findings that emerged from the data at the individual level. The coding of the interview notes was conducted by the first author (using NVIVO software), in consultation with the co-authors on the categorization of the data.

3 RESULTS

3.1 Sample characteristics

Descriptive statistics of the patient and family caregiver samples are presented in Table 1. The average age of patients was similar in the Chinese-speaking and Anglophone groups, 57 and 56, respectively. Family caregivers in the Chinese-speaking group were much younger (mean age 39 years) than those in the Anglophone group (mean age 62 years). The mean scores of patient distress were lower in the Chinese-speaking group than in the Anglophone group, whereas the mean scores of family caregiver distress were approximately equal in both groups. For patients, the mean QOL scores were higher in the Chinese-speaking group than in the Anglophone group, where Chinese-speaking patients reported higher physical, emotional, and functional well-being than patients in the Anglophone group.

Among the interviewees, there were more female than male patients (7 vs. 3) and an equal number of female and male family caregivers. The patients were largely immigrants from Hong Kong (7) who were 50 years or older. Similarly, most family caregivers were also born in Hong Kong (5); all, except one, were younger than 50 years old. The family caregivers interviewed included spouses, children and relatives of the patient; four had provided care to the patient for less than one year at the time of the interview. The demographic characteristics of the interviewees are summarized in Table 2. The corresponding number associated with each patient and family caregiver unique participation number (ID) represented dyads in the interviews.

3.2 Associations of patient QOL and distress

In the bivariate analyses, patient age was negatively associated with patient distress and positively associated with QOL total, social well-being and emotional well-being in the combined sample. Although family caregiver distress was not found to be associated with any of the patient QOL variables in the study, the conceptual relevance of the distress variable in the study framework warrants its

inclusion in the regressions for assessing the mediation effects of patient distress on patient QOL total, social well-being, and emotional well-being in the combined sample.

Regression analyses were conducted to examine the direct effects of factors relating to patient, illness-related, social/family and family caregiver on patient QOL, and the mediation effects of patient distress and family caregiver distress on patient QOL. Patient distress emerged as a strong predictor of patient QOL (β = -.79) with magnitudes of standardized coefficients across the domains of QOL ranging from -.45 to -.76 (see Table 3). Patient age was also directly associated with patient distress. After controlling for other covariates, patient age remained a significant predictor of patient emotional well-being in the combined sample, such that older patients had higher emotional functioning (β = .30). Family caregiver distress was, however, not significantly associated with patient QOL or any of the QOL domains in the Chinese-speaking group, the Anglophone group or in the combined sample; caregiver distress was also not found to be associated with patient distress.

Results of the mediation effects found in the analyses are presented in the path diagrams in Figure 2. The effects of patient age on patient QOL total were nearly completely mediated by patient distress (90% of the total effect was mediated by distress; see model 1). Examining the mediation effects in the QOL subscales, 50% of the total effect of patient age on patient social well-being could be attributed to mediation, where patient distress partially mediated the positive effect of patient age on social well-being (model 2). Similarly, the effect of patient age on patient emotional well-being was partially mediated (53%) by patient distress (model 3). No mediation effects were detected in the sub-group analyses of Chinese-speaking and Anglophone patients.

The same analyses were conducted based on complete case analysis and the results were consistent.

3.3 Interrelationships among patient distress, family caregiver distress and patient QOL

Qualitative analysis of the semi-structured interviews provided further insights about the interrelatedness between patient distress and family caregiver distress, and its impact on patient QOL. When speaking of their distress, some family caregivers commented that family members were more worried than the patients. In response to the news of the cancer diagnosis, one female family caregiver (CC4) caring for her husband diagnosed with prostate cancer said this of herself: "Very unhappy. I am more unhappy than him (patient)." Later in the interview, she described her distress when a post-surgery acute incident prompted the patient to be admitted to the emergency unit: "It was the most difficult…I felt isolated (*gu duk*) and helpless (*mou zo*)". Another female family caregiver (CC18) observed that her father appeared to be more distressed than her mother, who was diagnosed with colon cancer: "Dad was not eating…he looks more sick than Mom".

The reciprocal reaction of patient and family caregiver was highlighted when some family caregivers spoke of concealing their emotions from the patients. In response to her mother's diagnosis of colon cancer, a female family caregiver (CC18) said: "I almost didn't know how to respond…I would show my concern and anxiety to everyone else but her (mother)." The caregiver further described herself to be "playing it up" and "trying to act" when she was with her mother. Speaking of the family's reaction to her cancer diagnosis, the family caregiver's mother (CP18), noted her daughter's and other family members' attempt to downplay their distress, in their interaction with her. The patient further commented that she was aware that family members were attempting to put up a strong front in her presence, when she observed that they were "overly calm" in response to the news of her cancer diagnosis.

As family members sought to conceal their emotions from the patients, some patients also spoke of hiding their distress when they were with family members, further illustrated the interrelatedness of

patient and family distress and QOL. One male patient (CP6) said that when his daughters visited him at the hospital, he "pretended" he had no pain, to assure and "cheer them up." He further said he did not reveal much of his negative emotions, so as not to affect others, adding "I do not want others' emotion to affect me," and that "there is no point when everyone could not be happy." To alleviate anxiety in the family, a female patient (CP15) said that she did not use the word "cancer" when speaking with her 10-year old daughter. The patient also said that she always smiled in her daughter's presence, seeking to "console and cheer her up."

4   DISCUSSION

This study advances current literature on the understanding of the relationships among patient distress, family caregiver distress, and patient QOL in a sample of Chinese-speaking and Anglophone families dealing with cancer.

4.1 Mediation of age on patient QOL

The regression analyses reveal that greater distress in patients is associated with lower QOL of patients in both language groups. This finding is congruent with literature that examines the adverse impact of psychological distress on health-related outcomes and QOL (Kim et al., 2008; Mehnert & Koch, 2008). Regardless of the cultural and linguistic background of patients, cancer may be understood as a serious illness that challenges the order of the individual's world, spanning the domains of the person's QOL.

The mediated effects of patient age on patient emotional well-being found in this study also aligns with findings in past research in which older patients reported lower emotional distress and better QOL in the mental health domain following a cancer diagnosis (Mehnert & Koch, 2008; Thomas, NandaMohan, Nair, & Pandey, 2011). In light of the impact of age and distress on QOL, Nishigaki and colleagues assert that life stages, as they relate to changes in the individual's social and personal roles,

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should be considered when examining the psychological adjustment of cancer patients (Nishigaki et al., 2007).

When investigating the narratives of older women diagnosed with breast or gynaecological cancer, the findings from Sinding and Wiernikowski suggest that a long life of hardship may provide a context for the assessment of cancer as non-disruptive (Sinding & Wiernikowski, 2008). While the life experiences of older patients may have enhanced their capacity to adapt in times of distress, the roles and responsibilities of younger patients in their respective life stages may conversely add to their burden in managing the disease (Rosen, Rodriguez-Wallberg, & Rosenzweig, 2009). In response to literature suggesting older people already living with illness may experience cancer as less disruptive, Sinding and Wiernikowski recommend that researchers be cognizant of the influence of demographic characteristics in people's construction of their chronic illness experience (Sinding & Wiernikowski, 2008). To this recommendation, we add that cultural characteristics also be considered.

4.2 Interrelatedness of patient and family caregiver distress

Notwithstanding the conceptual importance of the role of the family caregiver in the patient's coping with serious illness, associations of family caregiver distress with patient distress and patient QOL were not supported by the results of the quantitative analyses. There may be several reasons for the lack of evidence in the current study to support these associations. Family caregivers in both the Chinese-speaking and Anglophone groups reported lower distress, compared to the patients. This sample of less distressed family caregivers may reflect a selection bias; family caregivers who volunteered to participate in the study may have in fact experienced less distress at the time of study enrolment or they may have been less inclined to report their distress. The family caregiver sample is also much smaller than that of the patients, resulting in less power to detect an effect.

While the quantitative results regarding the role of family caregiver distress is inconclusive, the qualitative findings provide insights about the reciprocal relationship between family caregiver and patient distress reported in past studies. The comment of family caregivers being "more distressed" than the patients raised by some female family members interviewed in the study may be pointing to the family caregivers' feelings of helplessness while wrestling with limitations in relieving their loved ones' suffering. Conceivably, the interrelatedness between the patient and family caregiver distress is a significant source of tension for both patient and caregiver throughout the illness trajectory, where the burden of caregiving adversely impacts the quality of care rendered (Milbury, Badr, Fossella, Pisters, & Carmack, 2013; Northouse et al., 2012; Segrin & Badger, 2014; Tan, Molassiotis, Lloyd-Williams, & Yorke, 2018). For the caregivers in the Chinese families who seek to provide care by protecting their ill loved ones from the physical and mental pain of cancer, the tension arising from feeling helpless may be more vexing, adding to the burden of caregiving (Lee & Bell, 2011; Lee et al., 2018).

In the interviews, both patients and family caregivers described situations where they sought to maintain a positive front by concealing their negative emotions from each other, in order to protect each party from further distress. The findings on the concealment of negative emotions in the family, following the diagnosis of a life-threatening illness, is consistent with other literature on the family caregiver's experience of cancer (Heidenreich, Koo, & White, 2014; Lee & Bell, 2011; Lee et al., 2018; Zahlis & Lewis, 2010). Notably, safeguarding the well-being of members in the family is a priority in coping with cancer. Further, maintaining harmony in the family unit may also be fundamental to the beliefs and values in some Chinese families. The quest for harmony is congruent with the notion of preserving stability, and for some Chinese people, it may also be deemed a virtue to be upheld in an individual's life and in the family (Ching, Martinson, & Wong, 2012). To regulate the level of distress in

the family following a cancer diagnosis, patients and family caregivers both assumed the responsibility to safeguard each other's mental health, upholding non-disclosure in the interest of the other.

4.3 Limitations

This study contributes to our understanding of differences in the experiences of cancer by patients and their family caregivers from different cultural or linguistic groups. However, several limitations warrant mentioning. Given the cross-sectional design, causality pertaining to the relationships between the distress and QOL variables hypothesized in the conceptual framework cannot be inferred. In this study, language was used as the key descriptor of the study populations. As such, patients and family caregivers of Chinese descent who did not speak Chinese were not represented in this research, and the cancer experiences investigated are limited to a segment of the broader Canadian Chinese population. In addition, results may have been influenced by self-selection bias and limited sample size.

5   CONCLUSIONS

This study examined an important topic pertinent to the care of an understudied population of Chinese-speaking cancer patients and family caregivers in Canada, a country with an increasingly diverse population. The findings shed light on the mediation effects of patient distress on patient QOL, where lower distress in older patients explained better social and emotional functioning. Given that age may be a factor affecting distress and a patient's QOL, it is recommended to tailor interventions with patients and family members in younger and older age groups, to address the specific concerns that align with their experiences of cancer. Further, the interrelatedness of patient distress and family caregiver distress found in the qualitative analyses highlights the emotional reactions to cancer within a family unit. It follows that there is a recognized benefit to offer supportive cancer care with the patient-family caregiver dyad, as the unit of care. With the prevalence of Chinese immigrants across the world,

more research in the Chinese immigrant populations in other countries is needed. Where cultural values and beliefs define help-seeking behaviours, understanding of the cultural and social context of ill persons and family members is foundational to patient- and family-centred care.

References

Almutairi, A. F., Dahinten, V. S., & Rodney, P. (2015). Almutairi's Critical Cultural Competence model for a multicultural healthcare environment. *Nursing Inquiry, 22*(4), 317-325. doi:10.1111/nin.12099

Cella, D. F., & Tulsky, D. S. (1993). Quality of Life in Cancer: Definition, Purpose, and Method of Measurement. *Cancer Investigation, 11*(3), 327-336.

Cella, D. F., Tulsky, D. S., Gray, G., Sarafian, B., Linn, E., Bonomi, A., . . . Brannon, J. (1993). The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *Journal of Clinical Oncology, 11*(3), 570-579.

Cheng, H. L., Sit, J. W. H., Chan, C. W. H., So, W. K. W., Choi, K. C., & Cheng, K. K. F. (2013). Social support and quality of life among Chinese breast cancer survivors: Findings from a mixed methods study. *European Journal of Oncology Nursing, 17*(6), 788-796.

Ching, S. S. Y., Martinson, I. M., & Wong, T. K. S. (2012). Meaning Making: Psychological Adjustment to Breast Cancer by Chinese Women. *Qualitative health research, 22*(2), 250-262. doi:10.1177/1049732311421679

Cohen, J. (1992). A power primer. *Psychological Bulletin, 112*(1), 155-159.

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (1995). Writing Ethnographic Fieldnotes. *Chicago: University of Chicago Press*.

Given, B., Sherwood, P., & Given, C. (2011). Support for Caregivers of Cancer Patients: Transition After Active Treatment. *Cancer Epidemiology Biomarkers & Prevention, 20*(10), 2015-2021.

Graham, J. (2012). *Missing data: Analysis and design*. New York: Springer.

Heidenreich, M. T., Koo, F. K., & White, K. (2014). The experience of Chinese immigrant women in caring for a terminally ill family member in Australia. *Collegian, 21*(4), 275-285. doi:http://dx.doi.org/10.1016/j.colegn.2013.06.002

Ho, S. M. Y., Saltel, P., Machavoine, J., Rapoport-Hubschman, N., & Spiegel, D. (2004). Cross-cultural aspects of cancer care. In R. J. Moore & D. Spiegel (Eds.), *Cancer, culture, and communication.* (pp. 157-183). New York: Plenum Publishers.

Kessler, R. C., Barker, P. R., Colpe, L. J., Epstein, J. F., Gfroerer, J. C., Hiripi, E., . . . Zaslavsky, A. M. (2003). Screening for serious mental illness in the general population. *Archieves of General Psychiatry, 60*, 184-189.

Kim, Y., & Given, B. (2008). Quality of life of family caregivers of cancer survivors - Across the trajectory of the illness. *Cancer, 112*(11), 2556-2568. doi:Doi 10.1002/Cncr.23449

Kim, Y., Kashy, D., Wellisch, D., Spillers, R., Kaw, C. K., & Smith, T. (2008). Quality of Life of Couples Dealing with Cancer: Dyadic and Individual Adjustment among Breast and Prostate Cancer Survivors and

Their Spousal Caregivers. *Annals of Behavioral Medicine, 35*(2), 230-238. doi:10.1007/s12160-008-9026-y

Lee, J., & Bell, K. (2011). The Impact of Cancer on Family Relationships Among Chinese Patients. *Journal of Transcultural Nursing, 22*(3), 225-234.

Lee, J. W. K., Gotay, C., Sawatzky, R., & Kazanjian, A. (2018). Interrelatedness of Distress Among Chinese-Speaking Patients and Family Caregivers. *Cancer nursing, Publish Ahead of Print*. doi:10.1097/ncc.0000000000000620

Lee, M. D. (2007). Correlates of consequences of intergenerational caregiving in Taiwan. *Journal of advanced nursing, 59*(1), 47-56. doi:10.1111/j.1365-2648.2007.04274.x

MacKinnon, D. P. (2008). Introduction to statistical mediation analysis. *Taylor & Francis Group: New York*.

Mehnert, A., & Koch, U. (2008). Psychological comorbidity and health-related quality of life and its association with awareness, utilization, and need for psychosocial support in a cancer register-based sample of long-term breast cancer survivors. *Journal of psychosomatic research, 64*(4), 383-391. doi:http://dx.doi.org/10.1016/j.jpsychores.2007.12.005

Milbury, K., Badr, H., Fossella, F., Pisters, K. M., & Carmack, C. L. (2013). Longitudinal associations between caregiver burden and patient and spouse distress in couples coping with lung cancer. *Supportive Care in Cancer, 21*(9), 2371-2379.

Nishigaki, M., Oya, M., Ueno, M., Arai, M., Yamaguchi, T., Muto, T., & Kazuma, K. (2007). The Influence of Life Stage on Psychosocial Adjustment in Colorectal Cancer Patients. *Journal of Psychosocial Oncology, 25*(4), 71-87. doi:10.1300/J077v25n04_05

Northouse, L. (2005). Helping families of patients with cancer. *Oncology nursing forum, 32*(4), 743-750. doi:10.1188/05.ONF.743-750

Northouse, L., Katapodi, M., Schafenacker, A., & Weiss, D. (2012). The Impact of Caregiving on the Psychological Well-Being of Family Caregivers and Cancer Patients. *Seminars in oncology nursing, 28*(4), 236-245. doi:http://dx.doi.org/10.1016/j.soncn.2012.09.006

Northouse, L., Mellon, S., Harden, J., & Schafenacker, A. (2009). Long-term effects of cancer on families of adult cancer survivors. *In S.M. Miller, D.J. Bowen, R.T. Croyle & J.H. Rowland (eds). Handbook of Cancer Control and Behavioural Science. APA*.

Northouse, L., Mood, D., Kershaw, T., Schafenacker, A., Mellon, S., Walker, J., . . . Decker, V. (2002). Quality of life of women with recurrent breast cancer and their family members. *Journal of Clinical Oncology, 20*(19), 4050-4064.

Rombach, I., Rivero-Arias, O., Gray, A. M., Jenkinson, C., & Burke, Ó. (2016). The current practice of handling and reporting missing outcome data in eight widely used PROMs in RCT publications: a review of the current literature. *Quality of Life Research, 25*(7), 1613-1623. doi:10.1007/s11136-015-1206-1

Rosen, A., Rodriguez-Wallberg, K. A., & Rosenzweig, L. (2009). Psychosocial Distress in Young Cancer Survivors. *Seminars in oncology nursing, 25*(4), 268-277. doi:https://doi.org/10.1016/j.soncn.2009.08.004

Rubin, D. B. (1987). Multiple Imputation for Nonresponse in Surveys. J. Wiley & Sons, New York.

Segrin, C., & Badger, T. A. (2014). Psychological and physical distress are interdependent in breast cancer survivors and their partners. *Psychology, Health & Medicine, 19*(6), 716-723. doi:10.1080/13548506.2013.871304

Sinding, C., & Wiernikowski, J. (2008). Disruption foreclosed: older women's cancer narratives. *Health (London), 12*(3), 389-411. doi:10.1177/1363459308090055

Stenberg, U., Ruland, C. M., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psycho-oncology, 19*(10), 1013-1025. doi:10.1002/pon.1670

Tan, J. Y., Molassiotis, A., Lloyd-Williams, M., & Yorke, J. (2018). Burden, emotional distress and quality of life among informal caregivers of lung cancer patients: An exploratory study. *European journal of cancer care, 27*(1), e12691. doi:doi:10.1111/ecc.12691

Thomas, B. C., NandaMohan, V., Nair, M. K., & Pandey, M. (2011). Gender, age and surgery as a treatment modality leads to higher distress in patients with cancer. *Supportive Care in Cancer, 19*(2), 239-250. doi:10.1007/s00520-009-0810-4

Young, R., & Johnson, D. (2013). Methods for Handling Missing Secondary Respondent Data. *Journal of Marriage and Family, 75*(1), 221-234. doi:doi:10.1111/j.1741-3737.2012.01021.x

Yu, C. L. M., Fielding, R., Chan, C. L. W., Tse, V. K. C., Choi, P. H. K., Lau, W. H., . . . Sham, J. S. T. (2000). Measuring quality of life of Chinese cancer patients. *Cancer, 88*(7), 1715-1727. doi:10.1002/(SICI)1097-0142(20000401)88:7<1715::AID-CNCR28>3.0.CO;2-K

Zahlis, E. H., & Lewis, F. M. (2010). Coming to Grips with Breast Cancer: The Spouse's Experience with His Wife's First Six Months. *Journal of Psychosocial Oncology, 28*(1), 79-97. doi:10.1080/07347330903438974

Zhou, C., Chu, J., & Wang, T. (2008). Reliability and validity of 10-item kessler scale (K10) Chinese version in evaluation of mental health status of Chinese population. . *Chinese Journal of Clinical Psychology, 16*(6), 627-629.

Table 1: Descriptive summary of patients and family caregivers in combined sample, Chinese-speaking and Anglophone group[a]

	Combined Group (*N* = 57)[b]		Chinese Group (*n* = 29)[b]		Anglophone Group (*n* = 28)[b]	
	Patient (n = 55)	Caregiver (n = 40)	Patient (n = 28)	Caregiver (n = 18)	Patient (n = 27)	Caregiver (n = 27)
Variables	Mean (*SD*)					
QOL total	83.4 (17.6)	--	85.9 (17.2)	--	80.9 (18.0)	--
Physical well-being	20.9 (6.2)	--	21.7 (5.3)	--	20.2 (7.0)	--
Social well-being	24.0 (4.41)	--	23.7 (4.7)	--	24.3 (4.1)	--
Emotional well-being	18.9 (5.4)	--	20.3 (4.6)	--	17.5 (6.0)	--
Functional well-being	19.6 (5.9)	--	20.3 (5.6)	--	18.9 (6.3)	--
Distress total score	5.2 (4.7)	4.6 (4.6)	5.0 (4.3)	4.6 (4.6)	5.4 (5.1)	4.6 (4.7)
Age	58.6 (11.8)	50.7 (22.2)	57.5 (10.6)	39.2 (19.5)	56.2 (13.1)	62.5 (18.1)
Years lived in Canada	38.8 (21.4)	37.9 (26.8)	21.9 (9.7)	16.1 (11.8)	56.4 (15.3)	60.5 (17.3)
Months of caregiving	--	10.5 (6.3)	--	10.5 (7.2)	--	10.6 (5.2)
	Counts (%)					
Sex:						
Female[c]	45 (78.8)	25 (44.6)	23 (77.8)	15 (51.6)	22 (79.9)	10 (37.3)
Male	12 (21.2)	32 (55.4)	6 (22.2)	14 (48.4)	6 (20.1)	18 (62.7)
Education:						
Post-secondary[c]	19 (33.5)	18 (32.8)	6 (22.6)	5 (19.2)	12 (44.7)	13 (47.1)
High school	23 (39.4)	11 (18.5)	14 (47.1)	4 (13.2)	9 (31.4)	7 (23.9)
University or advanced degree	15 (27.1)	28 (48.7)	9 (30.3)	20 (67.6)	7 (23.9)	8 (29.0)
English fluency:						
Beginner or intermediate[c]	21 (37.1)	12 (21.4)	21 (73.3)	12 (39.9)	0 (0)	1 (2.3)
Advanced	36 (62.9)	45 (78.6)	8 (26.7)	17 (60.1)	28 (100)	27 (97.7)
Patient-family caregiver relationship type:						
Extended family/relatives or close friends[c]	--	9 (16.1)	--	4 (15.3)	--	5 (16.9)
Spouse/partner	--	32 (56.1)	--	11 (36.8)	--	21 (76.1)
Children	--	16 (27.8)	--	14 (47.9)	--	2 (7.0)
Cancer site:						
Esophagus, lung, lymphoma or nasopharyngeal[c]	7 (12.3)	--	3 (10.3)	--	4 (14.2)	--
Breast	28 (49.1)	--	16 (55.2)	--	12 (42.9)	--
Bladder or colorectal	13 (22.8)	--	6 (20.7)	--	7 (25.0)	--
Ovarian, prostate or uterine	9 (15.8)	--	4 (13.8)	--	5 (17.9)	--
Cancer stage:						
Stage I	14 (24.6)	--	6 (20.7)	--	8 (28.6)	--
Stage II[c]	18 (31.5)	--	8 (27.6)	--	10 (35.7)	--
Stage III	25 (43.9)	--	15 (51.7)	--	10 (35.7)	--
Treatment type:						
Chemotherapy, drugs, radiation or surgery[c]	14 (25.4)	--	6 (20.6)	--	9 (30.4)	--
More than 1 treatment type	43 (74.6)	--	23 (79.4)	--	19 (69.6)	--

Note. [a] = Results based on multiple imputation. [b] = sample size based on multiple imputation for missing dyads. [c] = referent in the regression analyses

Table 2: Characteristics of interview participants

ID	Chinese Patients (CP)	ID	Chinese Caregivers (CC)
CP1	Female in 50s; migrated from Hong Kong 18 years ago; has university degree; diagnosed with Stage III nasopharyngeal cancer; 1 adult child	CC1	Male in 20s; migrated from Hong Kong 18 years ago; has post-secondary education; provided care to patient (mother) for 11 months
CP2	Female in 60s; migrated from Hong Kong 25 years ago; has high school education; diagnosed with Stage III ovarian cancer; 3 adult children	CC2	Female in 60s; migrated from Hong Kong 25 years ago; has master's degree; provided care to patient (sister-in-law) since the first diagnosis of breast cancer 7 years ago
CP4	Male in 50s; migrated from Hong Kong 19 years ago; has high school education; diagnosed with Stage III prostate cancer; no children	CC4	Female in 40s; migrated from Hong Kong 16 years ago; has post-secondary education; provided care for patient (husband) for 12 months.
CP5	Female in 60s; migrated from China 41 years ago; has master's degree; diagnosed with Stage III ovarian cancer; 2 adult children		--
CP6	Male in 60s; migrated from Hong Kong 40 years ago; has university degree; diagnosed with Stage III lung cancer; 4 adult children		--
CP7	Female in 60s; migrated from China 19 years ago; has university degree; diagnosed with Stage I or II breast cancer; 1 adult child.		--
CP9	Male in 60s; migrated from Hong Kong 15 years ago; has high school education;		--

ID	Chinese Patients (CP)	ID	Chinese Caregivers (CC)
	diagnosed with stage III colorectal cancer; 1 adult child		
	--	CC10	Male in 30s; migrated from Hong Kong 19 years ago; has university degree; provided care for patient (mother) for 9 months.
CP15	Female in 40s; migrated from Hong Kong 8 years ago; has high school education; diagnosed with Stage I or II breast cancer; 2 young children	CC15	Male in 40s; migrated from Hong Kong 8 years ago; has master's degree; provided care for patient (wife) for 7 months.
CP18	Female in 50s; migrated from Hong Kong 39 years ago; has post-secondary education; diagnosed with Stage III colon cancer; 3 adult children	CC18	Female in 20s; born and raised in Canada; has university degree; provided care for patient (mother) for 10 months.
CP21	Female in 50s; migrated from Taiwan 18 years ago; has university degree; diagnosed with Stage I breast cancer; 2 adult children.		--

Table 3: Direct effects of patient distress on QOL

Model: Dependent variable Independent variables	Combined Sample ($n = 57$) β	Chinese Group ($n = 29$) β	Anglophone Group ($n = 28$) β
Model 1: QOL total			
Patient distress	-.79**	-.79**	-.79**
Caregiver distress	-.03	-.07	-.02
Patient age	.03	.09	.01
Adjusted R^2	(.62, .69)**	(.46, .60)**	(.70, .74)**
Model 2: Physical well-being			
Patient distress	-.64**	-.46*	-.76**
Caregiver distress	.19	.03	.32
Stage I cancer (vs Stage II cancer)	-.08	.05	-.20
Stage III cancer (vs Stage II cancer)	-.15	-.26	-.12
Adjusted R^2	(.31, .48)**	(.25, .48)*	(.39, .51)**
Model 3: Social well-being			
Patient distress	-.49**	-.63**	-.45*
Caregiver distress	-.12	-.12	-.19
Patient age	.09	.20	-.04
Patient with high school education (vs post-secondary)	-.31*	-.46*	-.14
Patient with university/advanced degree (vs post-secondary)	-.09	-.16	-.10
Adjusted R^2	(.32, .37)	(.32, .49)*	(.19, .32)
Model 4: Emotional well-being			
Patient distress	-.68**	-.66**	-.65**
Caregiver distress	.02	-.06	.02
Patient age	.3**	.28	.07
Years patient lived in Canada	-.19	-.30	.47
Adjusted R^2	(.56, .67)**	(.41, .66)**	(.67, .74)**
Model 5: Functional well-being			
Patient distress	-.64**	-.69**	-.59**
Caregiver distress	-.18	-.12	-.23
Adjusted R^2	(.38, .53)**	(.32, .59)**	(.34, .54)**

Note. Range of adjusted R-square values based on multiple imputation. β = standardized regression coefficients *$p < .05$, **$p < .01$.

Figure 1: Conceptual framework of distress and quality of life of cancer patients and family caregivers
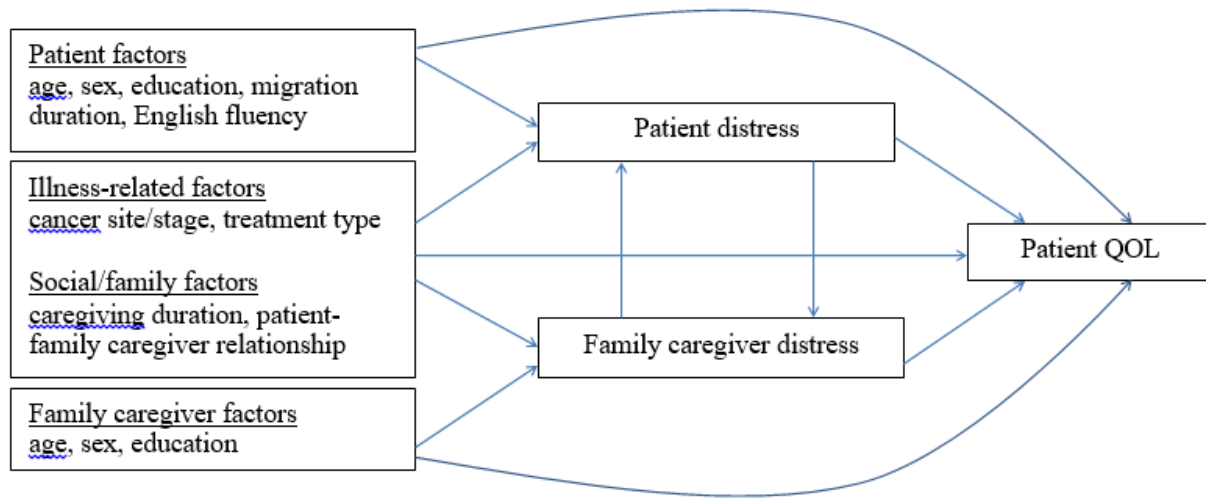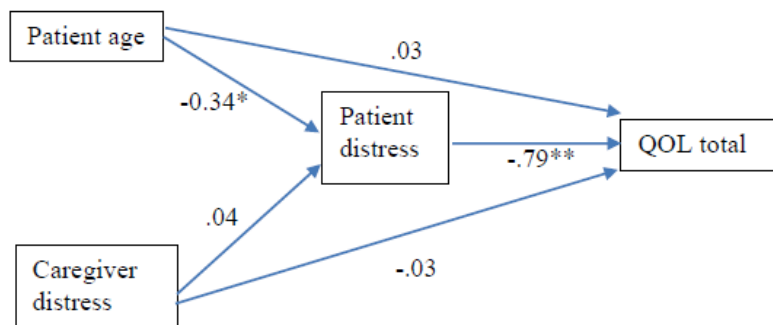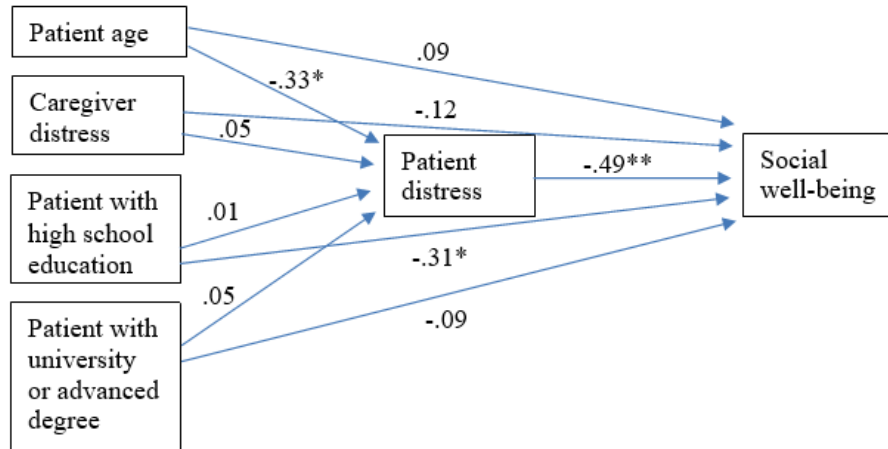

Figure 2: Mediation models of standardized regression coefficients

Model 1: Indirect effects of patient age on QOL total through patient distress, combined sample
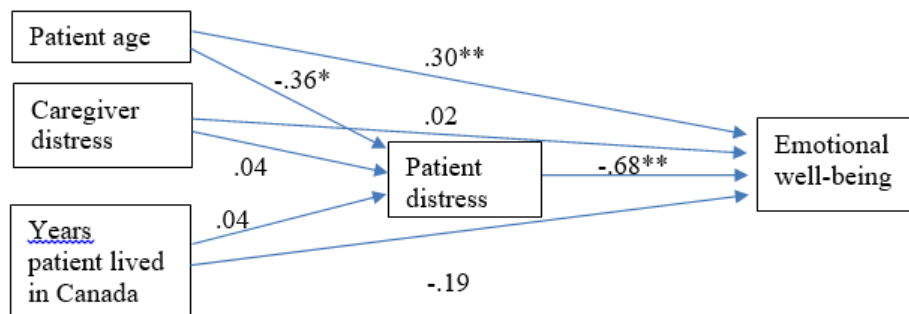

$*p < .05, **p < .01$

Model 2: Indirect effects of patient age on social well-being through patient distress, combined sample

Patient age → .09 → Social well-being
Patient age → -.33* → Patient distress
Caregiver distress → -.12 → Social well-being
Caregiver distress → .05 → Patient distress
Patient with high school education → .01 → Patient distress
Patient distress → -.49** → Social well-being
Patient with university or advanced degree → .05 → Patient distress
-.31*
-.09

*p < .05, **p < .01

Model 3: Indirect effects of patient age on emotional well-being through patient distress, combined sample

Patient age → .30** → Emotional well-being
Patient age → -.36* → Patient distress
Caregiver distress → .02 → Emotional well-being
Caregiver distress → .04 → Patient distress
Years patient lived in Canada → .04 → Patient distress
Patient distress → -.68** → Emotional well-being
-.19

*p < .05, **p < .01