Cultural Syndromes and the Appraisal of Common Cancer-Related Stressors

by

Ada Yui Man Payne

A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy

Institute of Medical Science
University of Toronto

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Abstract

Cultural values provide a system for evaluating situations we encounter; yet, they have seldom been tested in psychosocial oncology. The present research addressed this gap by testing the hypothesis that cancer-related events are stressful because they threaten highly regarded cultural values. As part of a larger study, 417 Western-born Caucasians and 121 Asian-born Chinese immigrants with head and neck cancer (HNC) completed the Individualism-Collectivism Scale (ICS), which measures their endorsement of four cultural syndromes (i.e., vertical-individualism, horizontal-individualism, vertical-collectivism, and horizontal-collectivism). However, the ICS did not tap these constructs identically across these samples. Consequently, I extracted a new common 3-factor measurement model: (a) Camaraderie with Co-workers; (b) Commitment to Family; and (c) Competitiveness. I cross-validated the new model in the HNC samples from which it was derived and in three independent chronic-disease samples. In all cases, results indicated weak invariance. To test the hypothesis, respondents reported the causes of stress (i.e., stressor appraisals) for 24 common HNC-related events. Stressor appraisals reported by a subset of respondents (196 Western-born Caucasians and 44 Chinese immigrants) were categorized based on whether they reflected threats to the cultural values tapped by the new scales. Because only stressor appraisals reflecting threats to commitment to family were identified, I tested the
association between commitment to family and the numbers of stressor appraisals reflecting threats to that value. Hierarchical Poisson regression analysis indicated a significant Culture Group x Commitment to Family interaction effect ($p = .045$): the number of stressor appraisals reflecting threats to commitment to family increased with increasing sense of commitment to family in Chinese immigrants, but not in Western-born Caucasians. Hence, cultural values, in part, explain cross-cultural variation in the experience of cancer stresses. Attention to cultural values can facilitate culturally sensitive patient-centered care by identifying culturally specific causes of stress for targeted psychosocial interventions.
Acknowledgments

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To Mom and Dad, thank you for instilling the importance of education in me. Your continual support was invaluable over the course of my training.

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<td>AGFI</td>
<td>Adjusted goodness-of-fit index</td>
</tr>
<tr>
<td>AIC</td>
<td>Akaike Information Criterion</td>
</tr>
<tr>
<td>BIC</td>
<td>Bayesian Information Criterion</td>
</tr>
<tr>
<td>CFA</td>
<td>Confirmatory factor analysis</td>
</tr>
<tr>
<td>CFI</td>
<td>Comparative fit index</td>
</tr>
<tr>
<td>COL</td>
<td>Collectivism</td>
</tr>
<tr>
<td>CRSC</td>
<td>Cancer-Related Stressor Checklist</td>
</tr>
<tr>
<td>DM</td>
<td>Diabetes Mellitus</td>
</tr>
<tr>
<td>EFA</td>
<td>Exploratory factor analysis</td>
</tr>
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<td>ESRD</td>
<td>End-stage renal disease</td>
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<td>HC</td>
<td>Horizontal-collectivism</td>
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<td>HI</td>
<td>Horizontal-individualism</td>
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<td>HNC</td>
<td>Head and neck cancer</td>
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<td>HOR</td>
<td>Horizontal dimension</td>
</tr>
<tr>
<td>ICS</td>
<td>Individualism-Collectivism Scale</td>
</tr>
<tr>
<td>IND</td>
<td>Individualism</td>
</tr>
<tr>
<td>LM</td>
<td>Lagrange Multiplier tests</td>
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<tr>
<td>MACS</td>
<td>Means and covariance structures</td>
</tr>
<tr>
<td>MSAS</td>
<td>Memorial Sloan-Kettering Symptom Assessment Scale</td>
</tr>
<tr>
<td>MSCFA</td>
<td>Multi-sample confirmatory factor analysis</td>
</tr>
<tr>
<td>NNFI</td>
<td>Non-normed fit index</td>
</tr>
<tr>
<td>QOL</td>
<td>Quality of life</td>
</tr>
<tr>
<td>RA</td>
<td>Rheumatoid arthritis</td>
</tr>
<tr>
<td>RMSEA</td>
<td>Root mean-square error of approximation</td>
</tr>
<tr>
<td>rob</td>
<td>Robust fit indices</td>
</tr>
<tr>
<td>SB</td>
<td>Satorra-Bentler scaled $\chi^2/df$ ratio</td>
</tr>
<tr>
<td>SRMR</td>
<td>Standardized root mean squared residual</td>
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<tr>
<td>VC</td>
<td>Vertical-collectivism</td>
</tr>
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<td>VERT</td>
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Chapter 1
Overview of the literature

“Illness” represents the subjective experience of observable disease processes, which may include emotional and psychosocial effects [1,2]. This subjective element contributes to variation in experiences among individuals diagnosed with cancer. The lay definition of cancer, which is “a malignant tumor of potentially unlimited growth that expands locally by invasion and systemically by metastasis” [3], implies biological uniformity. However, an abundance of literature has documented substantial diversity in the cancer experience (for overview, see [4]). Culture is likely a significant contributing factor to this diversity.

As with other life experiences, we perceive, understand, and experience illness in a cultural context [5]. Depending on the culture, we acquire various explanatory models of disease [6-8], emphasize different symptoms [9], and perceive and describe illness in varying terms [6,10]. Cultural influences may be particularly evident when conditions, such as head and neck cancer (HNC), are prevalent in people from diverse geographic regions.

HNC introduces threatening psychosocial implications [11]. Whether these are perceived as stressful may depend on the extent to which they threaten deeply held culturally based values and beliefs. For example, good health is important to those with predominantly collectivist values because it provides a means to fulfill social obligations [5]. In this context, HNC may be perceived as threatening when it prevents people from fulfilling social roles and responsibilities, such as caregiver or breadwinner. For those with predominantly individualist values, on the other hand, good health is valued because it facilitates self-actualization and is the expression of personal autonomy [5]. These individuals may perceive HNC as a threat because it reduces the ability to fend for oneself, resulting in the loss of independence [5,12]. Although culture very likely plays an important role in the psychosocial impact of HNC, little research has examined this issue. This thesis aims to investigate the association between culture and the appraisal of HNC-related events as stressful.

Several issues will be examined before addressing this gap in research: (a) the psychosocial impact of HNC; (b) the conceptualization and measurement of culture; and (c) cancer appraisal in cross-cultural context.
1.1 Head and neck cancer

HNC most commonly involves malignancies located in squamous cells of the lips, in the mouth, pharynx, larynx, saliva glands, paranasal sinuses, and skin of the head and neck region [11,13]. It is mostly attributed to heavy use of tobacco (including smoking and chewing tobacco) and alcohol [14,15], and increasingly, to exposure to Human papillomavirus [16]. Some of the common symptoms include a lump or sore that does not heal, a persistent sore throat, difficulty swallowing, and a change or hoarseness in the voice [13].

1.1.1 Prevalence, treatments, and side effects

HNC is the sixth most common cancer worldwide [17]. Incidence is highest in Southern Asia and in Central and Southern Europe [14]. Nasopharyngeal cancer, a subtype of HNC, is very common in Southern China [18]. As compared to native-born residents, nasopharyngeal cancer incidence remains higher in Chinese immigrants who emigrate to low-incidence countries, such as Canada [18,19]. India has the highest global incidence of oral cancer, whereas European countries, such as Spain and Italy, exhibit intermediate rates [20]. Lip cancer is most prevalent in Caucasian populations in Canada and Australia [20]. In Canada, there was an estimated 5,050 new cases of and 1,540 deaths from oral and laryngeal cancers in 2012 [21]. Between 2001 and 2005, the age-standardized, 5-year relative survival of oral cavity and pharynx cancers in Ontario, Canada was 62% [22].

The typical treatment regimen includes any combination of surgery, chemotherapy, and radiotherapy. Each treatment is associated with many side effects. People who undergo surgery for HNC can experience difficulties in speech, swallowing, and/or eating due to alterations in the oral cavity structure, xerostomia (dry mouth), and trismus (limited ability to open the mouth due to scar tissues) [13,23]. Facial features may be disfigured, especially when treatment involves: (a) the installation of a stoma (external opening to the trachea) following laryngectomy, which involves removal of the larynx [24], or (b) a facial prosthesis after surgery for cancers in the nasal cavity or paranasal sinus [25]. Common chemotherapy side effects include sores in the mouth and on the lips, lower resistance to infections, loss of appetite, vomiting, nausea, diarrhea, and hair loss [13]. Those who receive radiotherapy can experience side effects that include redness, irritation, or sores at the radiation site, xerostomia or thickened saliva, dysphagia
(swallowing difficulties), changes in taste, and/or nausea [13]. Many people with HNC receive more than one of these types of treatments, increasing the likelihood of multiple side effects.

1.1.2 Psychosocial stressors

Many studies concerning the psychosocial impact of HNC focus on cancer- and treatment-related concerns or stressors. Physical symptoms such as xerostomia, dysphagia, and trismus are among the most commonly identified and most stressful concerns [26-30]. Related to these physical symptoms are dysfunctions, such as speech and eating difficulties. Other physical stressors include pain and fatigue [31,32]. Ashbury et al. [33] surveyed a heterogeneous sample of Canadians with cancer (n = 899; including HNC) and found that 78% reported experiencing fatigue. Of those, 87% rated the severity as moderate to severe and 56% indicated “quite a bit” or “a great deal” of functional interference. A Swedish mixed-cancer sample, including people with HNC, reported that the most stressful issues for them were pain, uncertainty about the future, anxiety, and “uneasiness” [34]. Many of the physical stressors and concerns persist for years after diagnosis [35], although they do not necessarily compromise overall quality of life (QOL) [36-39].

Many people with HNC report concerns for the future. In one study, people with HNC (n = 101) reported fear of recurrence three and six months post-treatment [40]. In a small sample of Canadians with advanced cancer (n =52), a prevalent concern was “worry and concern about the future” (48%). Among those who reported this concern, 40% were concerned about death and dying and 17% were worried about the family’s future welfare [31].

In terms of social concerns, one of the most common stressors in HNC is its impact on interpersonal relationships [41]. Many with HNC find it difficult to manage changes in their ability to work, to continue to fulfill family responsibilities, or to do the things that are important to them, including leisure activities [32,42-44]. For example, “being a burden to others” and “role loss” were the most commonly reported social concerns in a Canadian sample [31]. Many experience financial difficulties as a result of reduced or lost income due to work disruption [45-47]. A Norwegian study indicated that men with HNC reported 17% income reductions, whereas women reported 16% reductions [48].
Some HNC-induced physical dysfunctions impede social interaction. Effects of HNC, such as disfigurement, are often highly visible because they occur on the face and head region [49]. Such changes can exert a substantial impact on interpersonal interactions. They can result in social withdrawal and avoidance of social-support network members, as well as changes in the sense of self (e.g., loss of self-esteem, changes in self-image and identity) [26,28,29,50-52]. Eating in social settings becomes uncomfortable and/or embarrassing because people with HNC require special diets or meal preparations post-treatment, such as purées. This can lead to withdrawal from meal sharing and losing the associated psychosocial benefits [53-55]. Eating difficulties can present a unique challenge for Chinese people because the offering of food is often employed to express love and concern [56-58].

Stigma, too, can affect social exchange. Often conceptualized as “felt stigma,” it refers to the internalization of shame and the fear of discrimination [59]. It is relevant in HNC because the disease is often attributed to risk-inducing behaviours that are within a person’s control, such as alcohol and tobacco use and having unprotected sex [60]. Stigma has been associated with distress and illness intrusiveness [44]—disease- and treatment-induced disruption of lifestyles, activities, and interests [61,62]. Disfigurement-related stigma is associated with increased distress and decreased life happiness [62]. Although received wisdom maintains that stigma is common in HNC [63], more recent research suggests that it may less common than believed [41,61].

1.1.3 Prevalence of psychosocial stressors among people from non-Western cultures

Although HNC is prevalent in different ethnic groups [14], many studies (e.g., [42]) cited in the previous section examined samples comprised primarily of Caucasians. Little is known about cancer-related concerns or stressors experienced by people who originate from non-Western cultures. Few studies have reported the prevalence of cancer-related stressors among people from non-Western cultures. The most common concerns in a sample of Hong Kong Chinese with HNC ($n = 128$), for example, were dry mouth (97%), choking (85%), and swallowing difficulties (85%) [64]. In a qualitative study of Chinese cancer patients, people expressed concerns about the disease’s impact on family and disruptions to the caregiver role [65]. Chaturvedi, Shenoy, Prasad, Senthilnathan, & Premlatha [66] surveyed an Indian sample with oral or laryngeal cancer ($n = 50$) and found that 50% or more of respondents reported concerns about the following: the
future, subjective evaluation of physical status, finances, communication, being upset, current illness, and inability to do things. Contrary to findings from people from Western cultures, one of the least prevalent concerns in the Indian sample is being dependent on others [66]. Because the prevalence of these HNC-related stressors have not been examined and compared directly between people from different cultures in the same study, it is remains unclear whether HNC-related stressors are experienced universally or whether some are more burdensome to people from particular cultures.

Some studies have examined whether cancer-related concerns differ between people of diverse ethnic origins in cancers other than HNC. In a group of women with breast cancer, Caucasians reported worrying most about loss of autonomy and incapacity, whereas African-, Latina-, and Asian-Americans reported most concerns about being unable to perform the caregiver role and the impact of this on their families [67]. Similar variations were observed in multi-ethnic samples of women with cervical cancer and dysplasia [68].

It appears that people of different ethnic/cultural backgrounds do not experience the same types of cancer-related psychosocial stressors. Current knowledge does not explain, however, why differences arise. Some scholars have attributed ethnic differences in cancer-related stressor experiences to differences in cultural values. Chaturvedi et al. [66] reasoned that the threat of dependency may not elicit stress or concern among Indian people with HNC because their culture expects family members to care for loved ones when they become ill. Before discussing the role of culture in shaping the experience of cancer, we must first articulate its conceptualization and address the related issue of measurement.

1.2 Culture: Conceptualization and measurement

Culture is a complex phenomenon. Scholars have proposed more than 100 different definitions [69,70]. Despite substantial differences, Taras et al. [71] distilled four common, conceptual elements. Culture is: (a) a multi-level construct with basic assumptions and values at the core, and practices and artifacts at the periphery; (b) shared among individuals within a group; (c) formed over a long period; and (d) relatively stable. For many years, researchers have attempted to study culture by seeking to understand how cultural traditions and social practices influence individual thinking and perception [72]. When applied in the context of health and disease, this knowledge offers valuable clinical insights into how and why people experience disease as they
do. This, in turn, can lead to more targeted, culturally sensitive interventions, which may be especially valuable in achieving patient-centered care [73].

1.2.1 Individualism and collectivism

Two widely studied cultural constructs are “individualism” (IND) and “collectivism” (COL). These concepts represent broad, underlying dimensions that differentiate Western and Eastern cultures. They have been used to explain why concepts, such as power [74], personality [75], and cognition [76], differ across people who have been socialized in different geographic regions. Although the concepts have fascinated scholars for decades, Hofstede’s [77] book, “Culture’s Consequences,” has been widely credited as a powerful impetus for the growth in IND-COL research [71,78]. The popularity of IND, and subsequently COL, has been attributed to their “theoretical parsimony” ([78], p. 44), because they subsume a very large number of cross-cultural variables under a small, more tractable number of dimensions. As a result, they offer valuable implications for understanding the psychosocial impact of HNC. Oyserman et al. [78] presented a detailed review and meta-analysis of these cultural syndromes. In the following sections, I will highlight how the conceptualization and measurement of IND and COL are relevant to the present study.

1.2.1.1 Conceptualization

IND and COL are “cultural syndromes,” which entail sets of attitudes, beliefs, and values that center around a common theme [79]. They are conceptualized as separate constructs with multiple elements [79-82]. Although many theorists have suggested diverse definitions for IND (e.g., [77,79,83]), its essence entails construing oneself as an independent entity [78]. Similarly, many definitions have been proposed for COL (e.g., [84-87]), but its core element is that individuals construe themselves as integrally tied to a reference group. Both IND and COL manifest through motivations and behaviours. Other comparable concepts include “independence-interdependence” [85] and “idiocentrism-allocentrism” [79]. Table 1 summarizes the essential characteristics of IND and COL [78,79]. Researchers have correlated IND-COL with values to which theory predicts they should relate. These findings provide evidence that the values implicit in the two cultural syndromes do correlate with independent measures of them. IND correlates positively with competition, self-reliance, emotional distance from in-groups, and hedonism [88-91]. IND is inversely associated with interdependence, sociability, and family
integrity. COL correlates positively with family integrity and sociality, and negatively with competition, emotional distance from in-groups, and hedonism [91].

Table 1. Characteristics of IND and COL

<table>
<thead>
<tr>
<th>Domain</th>
<th>IND</th>
<th>COL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-concept</td>
<td>• Self is defined as a unique entity, independent of others</td>
<td>• Self is defined as an interdependent part of a social group</td>
</tr>
<tr>
<td></td>
<td>• Maintenance of positive self-concept is important</td>
<td>• Valued personal traits reflect goals of COL (e.g., willingness to sacrifice for the common good)</td>
</tr>
<tr>
<td></td>
<td>• Personal achievements and having unique personal attributes are valued</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Self is described in terms of abstract traits (e.g., strong, intelligent)</td>
<td></td>
</tr>
<tr>
<td>Goal orientation</td>
<td>• Attainment of personal goals is top priority</td>
<td>• Fulfillment of social roles and obligations is top priority</td>
</tr>
<tr>
<td>Behavioural</td>
<td>• Personal traits explain behaviours</td>
<td>• Social role and context, situational constrains are taken into account when explaining behaviours</td>
</tr>
<tr>
<td>attribution</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationships</td>
<td>• Relationships are impermanent and non-intensive</td>
<td>• Important group memberships are fixed</td>
</tr>
<tr>
<td></td>
<td>• Relationships should help foster personal goal attainment</td>
<td>• In-group and out-group boundaries are stable, relatively impermeable, and valued</td>
</tr>
<tr>
<td></td>
<td>• They are prioritized and maintained at minimal personal cost</td>
<td>• In-group interactions are based on equality or generosity principles</td>
</tr>
</tbody>
</table>

IND and COL have been conceptualized as group- and individual-level variables. As group-level variables, these cultural syndromes describe a set of characteristics that reflect the important values, beliefs, attitudes, behaviours, and norms that characterize a group as a whole [92]; as individual-level variables, they describe personal preferences and inclinations for a set of values, beliefs, attitudes, and motivations that are believed likely to influence cognition, affect, and behaviours [81].

However, it would be inappropriate to assume isomorphism between different levels of measurement [93] because the group- and individual-level structures of IND-COL are influenced by different factors [94]. Group-level IND-COL (i.e., individualism-collectivism as a characteristic of a population) correlates with macro-level indicators, such as national wealth [69], extent of urbanization, and percentage of immigrants in a population [95], whereas individual-level IND-COL (i.e., individualism-collectivism as experienced by one, but not all
individuals) is associated with personal-level correlates such as independence [78], hedonism, and self-reliance [91]. Not all individuals within a group adhere to the same values to the same extent [79]. For instance, although the U.S. is considered an individualist society [78], not all Americans are highly individualistic. A recent meta-analysis indicated that European-Americans were higher in vertical-individualism (which emphasizes distinguishing oneself from others) than African- and Latino-Americans [96]. This suggests that group-level cultural characteristics of a society do not necessarily equate to the aggregation of individual Americans’ predominant cultural syndromes.

This issue is particularly relevant in IND-COL research because most instruments that measure these cultural syndromes tap individuals’ attitudes, values, and beliefs [71,78]. Failing to distinguish these two levels of measurement results in the error known as “reverse ecological fallacy”—i.e., drawing inferences about a group based on observations collected from the individuals who belong to them [69]. This misinterpretation can lead to unfortunate clinical implications. For example, culturally specific psychosocial interventions intended to accommodate to or address a given group’s values and beliefs may fail because individuals from the group participating in the intervention do not share the cultural syndromes that characterize the group as a collective (e.g., not all Americans are predominately individualistic [96]).

Although some have recommended using unique terms to designate individual-level concepts (e.g., idiocentrism and allocentrism for individual-level IND and COL respectively [79]), researchers continue to use the labels, IND and COL when discussing individual-level observations and analyses. To be consistent with the terms commonly used in the literature, I will use the terms, “IND” and “COL,” in this thesis despite the focus on individual-level variables and analyses.

People can hold both individualist and collectivist values [79,81]. It is variations in the extent to which people and culture groups adhere to diverse cultural syndromes that lead to cross-cultural differences [79,97,98]. Those from Western cultures tend to emphasize IND over COL, whereas the reverse is true for those from Eastern cultures [76,78,99]. For these reasons, behavioral and social scientists often select Western-born Caucasians to represent individualist societies and Asian-born Chinese to represent collective societies (e.g., [86,100-104]).
1.2.1.1.1 Vertical-horizontal dimension

IND and COL are multidimensional, broad cultural constructs that are useful in examining cross-cultural variations [105]. However, they may be too general to generate insights into the more specific relationships between cultural values and psychosocial phenomena [81,98,106]. Triandis [79,98] proposed that incorporating two additional cultural syndromes—vertical (VERT) and horizontal (HOR)—refines the conceptualization of IND-COL and improves their predictive power in relation to psychosocial phenomena [93]. VERT emphasizes hierarchy in social structure whereas HOR emphasizes equality. Other researchers have used the VERT-HOR typology in describing social groups (e.g., Fiske’s [107] categorization of sociality). By combining the IND-COL and VERT-HOR dimensions, Triandis proposed four new cultural syndromes: vertical-individualism (VI); horizontal-individualism (HI); vertical-collectivism (VC); and horizontal-collectivism (HC; see Table 2).

**Table 2.** Characteristics of VERT-HOR IND and COL

<table>
<thead>
<tr>
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<th>VERT</th>
<th>COL</th>
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<tr>
<td>VERT</td>
<td>• Emphasizes the improvement of individual status and distinguishing oneself from others (e.g., the United States)</td>
<td>• Emphasizes respect for authority and maintenance of social cohesion, even when self-sacrifice is necessary (e.g., China)</td>
</tr>
<tr>
<td>HOR</td>
<td>• Emphasizes equality in status, self-reliance, and expression of one’s uniqueness (e.g., Sweden)</td>
<td>• Emphasizes sociability and interdependence with others in an egalitarian environment (e.g., Israeli kibbutz)</td>
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As group-level variables, VERT-HOR resemble Hofstede’s concept of power distance; as an individual-level variable, both relate to personal values such as power, self-direction, conformity, and achievement [93]. Various values have been correlated with VERT-HOR IND and COL to establish their construct validity. VI correlates with competition and hedonism; VC with family integrity; HI with self-reliance; and HC with family integrity, sociability, and emotional distance from in-groups [91]. Others have reported that HI relates to self-direction, but VI does not. HC correlates most highly with benevolence, VC with conformity, VI with power, and HI with self-direction [108].

Most researchers conceptualize VERT-HOR as sub-types of IND and COL [93]; that is, VERT and HOR take different forms in the IND-COL context. For example, the VERT element
emphasizes attainment of individual status in VI, whereas it emphasizes deference to those higher in the social structure in VC. Indeed, some studies (e.g., [109,110]) and measurement models have examined these concepts as nested within the IND-COL framework, as proposed by Triandis [79,98]. One of such instrument is the Individualism-Collectivism Scale (ICS) [82,91], which is commonly used to measure VERT-HOR IND and COL.

Over past decades, scholars have relied on VERT-HOR IND and COL to explain cross-cultural differences in thoughts, motivations, emotions, and behaviours. Yet, the validity of empirical findings depends on the availability of psychometrically sound measures to characterize these cultural syndromes. Thus, it is crucial to establish that the instruments developed to tap them satisfy these fundamental criteria.

1.2.1.2 Measuring VERT-HOR IND and COL

Some general challenges in measuring culture are relevant to the measurement of VERT-HOR IND-COL (see [71,78] for comprehensive critical reviews). These include: (a) effective translation of English questionnaire-items into other languages; (b) replication of the underlying measurement models (e.g., factor structure); and (c) subscale internal consistency. Many instruments were developed and tested largely in undergraduate college students [71,78]. This raises questions about the generalizability of underlying measurement models to other populations. In this section, I briefly review these challenges in the abstract. This is followed by an in-depth examination of the ICS, in particular (see Section 1.2.1.2.1).

Instruments employed to tap VERT-HOR IND-COL are often translated from English to another language. This strategy, if effective, reduces measurement error attributed to language proficiency when employing the instrument in non-native English-speakers. Standard back-translation protocols (e.g., [111]) have often been used to translate English instruments to other languages. This procedure, however, can fail when: (a) items contain idioms, proverbs, or colloquialisms, or (b) there is no equivalent concept in the other languages [112]. Another problem arises when items include evaluative terms, such as “often.” Such phrases are ambiguous in the absence of an absolute reference point [112]. This can contribute to inconsistencies between English and translated versions.
Even when items have been translated accurately, non-equivalent factor structures between original and translated versions of a questionnaire can invalidate between-group comparisons. A factor structure describes the relations between a set of observed variables and corresponding latent variables [113]. It is said to be equivalent between groups when the items measure the same latent variable in the same way in different groups [114, 115]. Equivalence is tested at increasingly stringent levels of the factor structure: an instrument’s underlying factor structure may share the same (a) number of factors represented by the same items, (b) factor loadings, (c) item intercepts, and (d) error variances for each factor between targeted groups. Consistent demonstrations of measurement-model invariance across different samples enhance confidence that group-mean comparisons reflect true differences in the phenomenon of interest rather than measurement error.

Scale reliability introduces an important psychometric issue because it relates to the consistency of measurement [116, 117]. This, in turn, has implications for the dimensionality of measurement. Internal consistency (one facet of reliability) addresses the extent to which responses to the items that comprise a given scale correlate with each other. Strong internal consistency is observed when the items that comprise a scale or subscale measure a single concept because all correlate with each other [115, 116]. Various measures of IND-COL consistently display low internal consistency [71, 78]. The average Cronbach’s $\alpha$ across IND-COL instruments is less than .70 [78], which is below the threshold recommended for research purposes [118]. Some scale developers attribute this problem to the challenges intrinsic to measuring a complex construct using comparatively few items (e.g., [82]). Unfortunately, low reliability can undermine the validity of empirical observations. The development of scales that measure more specific elements of IND-COL can improve scale reliability [78].

A common participant-recruitment strategy in cross-cultural research is to use country of birth, ethnicity, or race as proxies for the cultural values and beliefs investigators wish to study (e.g., recruiting people of European descent to represent those with individualist values and those of Asian descent to represent those with collectivist values). However, recent research has shown that country of birth or ethnicity may not represent cultural values accurately [119]. For example, Japanese culture appears to be no more collectivist than American society [120, 121]. Contrary to its theoretical conceptualizations, IND is not associated with competitiveness at individual or national levels [122]. As a result, studies that adopt this strategy to operationally define culture
may inadvertently attribute group differences to the assumed association between cultural values and country of birth or ethnicity when this is not the case. A possible solution is to incorporate a direct measure of the cultural variable of interest to verify the underlying assumption or to use it as an explanatory variable in its own right.

In considering these measurement challenges, Taras et al. [71] and Oyserman et al. [78,81] recommend developing and utilizing instruments that tap specific aspects of culture and IND-COL, rather than employing global, multi-dimensional ones. Specifically, Oyserman et al. [78] advocated measuring the core element of IND (i.e., personal independence) and COL (i.e., duty to in-group) to achieve higher reliability and precision in measurement. Some have begun to move in this direction. COL-relevant concepts that have been studied include “familism” (i.e., prioritizing family needs and honour above one’s own, remaining respectful and obligated to family) [123,124], “relational self” (i.e., defining oneself in terms of the connections and role relationships shared with significant others) [125], “contextualism” (i.e., the belief that context is important in understanding people) [126]; IND-relevant concepts that have been examined include “autonomy” (i.e., one’s capability for independent thinking, judgment, and survival), “mature self-responsibility” (i.e., accepting responsibility for oneself and his/her actions, confidence in one’s abilities), and “uniqueness” (i.e., awareness of being different from others) [127]. Specific instruments are also more likely to detect systematic associations between culture and behaviour because they are more proximal to the outcome of interest than are broader constructs, such as IND-COL [81].

1.2.1.2.1 Individualism-Collectivism Scale

Many instruments have been developed to measure IND and COL (e.g., [82,128,129]). One of the most commonly used is the ICS [82]. It has been used to examine a wide range of issues in cultural psychology, including intergroup negotiations [130], work relationships [131], and the psychosocial impact of chronic disease [132]. It comprises four subscales: VI, HI, VC, and HC. Each comprises eight items that use a bipolar rating scale to tap agreement with representative statements (1 = “disagree very much” to 7 = “agree very much”).

1 The ICS version by Singelis, Triandis, Bhawuk, and Gelfand [82] used a 7-point rating scale, while a later version by Triandis and Gelfand [91] used a 9-point rating scale.
Despite its popularity, the ICS has experienced some of the challenges mentioned in the previous section. For example, Robert, Lee, and Chan [112] found that there was non-equivalence between the English and Korean versions of the ICS item, “I often ‘do my own thing,’” because it includes an English colloquialism of “do my own thing.” It has also shown poor measurement invariance and limited internal consistency, which can undermine the interpretation of findings (a more detailed review of the ICS appears in Chapter 4). The hypothesized 4-factor measurement model (i.e., VI, HI, VC, and HC) has not been verified consistently in English or in translated versions [108,133-135]. This suggests that ICS items may not tap the four concepts as hypothesized in its measurement model. It is important to note that these inconsistencies only raise questions about the invariance of the ICS factor structure; they do not invalidate the underlying theoretical constructs of IND and COL. Moreover, some subscales in English and translated versions of the ICS have failed to meet reliability criteria such as Cronbach’s $\alpha > .70$ [74,82,133,135,136]. IND and COL have proven useful in advancing knowledge in cultural psychology [81]. Yet, given consistent evidence of psychometric shortcomings, it is crucial to evaluate and, if indicated, revise the current measure to improve its ability to tap VERT-HOR IND and COL.

As is true of many measures of IND-COL, the ICS was developed and validated in healthy, college undergraduate samples (e.g., [71,78]). Because this population has unique social characteristics and life experiences [137], the generalizability of these psychometric findings to the broader, physically healthy or to chronically ill populations may be limited. Thus, before using the ICS to investigate how cultural syndromes shape the appraisal of cancer stressors, it is crucial to evaluate its psychometric adequacy in ill population. This will be undertaken in the Results chapters (see Chapters 4 and 5).

The next section addresses theoretical considerations about how cultural syndromes, such as VERT-HOR IND and COL, influence perceptions of cancer-related stressors. These theories inform the hypothesis for this thesis.
1.3 Culture and cancer-related stressor appraisal

1.3.1 Primary appraisal of cancer

Primary appraisal is a cognitive process that involves determining whether an event is relevant to and consistent with personal goals or motivations [138,139]. This process is crucial to our understanding of how people experience cancer-related stressors because it can shape the psychosocial impact and the coping efforts people adopt to manage them. Three types of primary appraisals have been hypothesized to determine the stressfulness of an event: (a) harm/loss, (b) threat, and (c) challenge [139]. Harm/loss appraisals arise when a person believes that an event has already caused damage to an important part of life. Threat appraisals anticipate the harm/loss that may result from the event, whereas challenge appraisals focus on the belief that difficulties may be overcome and that potential gains may result. An event may also be evaluated as benign (i.e., not stressful) or as positive [139]. Lazarus and Folkman [138,139] introduced the notion of secondary appraisal, a cognitive process by which people determine whether they have sufficient resources to deal effectively with a situation that is appraised to be a loss, harmful, threatening, or challenging. Because this study concerns the interpretation of cancer-related stressors, I will centre the discussion on primary appraisal.

Research demonstrates that people with cancer report all three types of primary appraisals in discussing their diseases [10,140-142]. For example, Wonghongkul et al. observed that women with breast cancer appraised their cancer as “highly” challenging, “somewhat” threatening, and “a little” harmful ([143], p. 254). Cancer may be appraised as threatening because it can prevent people from achieving personal goals [141]. It may be seen as a challenge because people can learn from cancer-related experiences, leading to positive changes in their lives. If they have already encountered social limitations or financial difficulties, people with cancer may appraise the condition in terms of loss. Appraising cancer as a threat has been associated with distress in colorectal cancer survivors [144], corroborating the presumption that threat appraisals play an important role in the psychosocial impact of cancer.

Several instruments have been developed to assess primary appraisals, as defined in Lazarus and Folkman’s [139] framework. The Stress Questionnaire [145] rates the extent to which respondents experience four appraisal-related emotions: threat emotions (e.g., worried; 3 items); challenge emotions (e.g., confident; 3 items); harm emotions (e.g., angry; 5 items); and benefit
emotions (e.g., pleased; 4 items). A summary score for each subscale reflects the tendency for respondents to engage in each type of appraisal. However, because the Stress Questionnaire relies on emotional reactions as proxies for cognitive appraisals, it does not explain how people come to experience these emotions.

Browne et al. [146] assessed the psychometric properties of the Meaning of Illness Questionnaire. Of the 33 items, four specifically tap the extent to which respondents perceive their illness as harm, loss, threat, or challenge. Because only a single item taps each type of appraisal, it is difficult to rule out possible variations in the interpretation of the item, which can result in mistaking measurement error as reflecting “true” appraisal variance.

Peacock and Wong [147] developed the Stress Appraisal Measure by employing undergraduate students as respondents. It measures anticipatory stress—stress associated with events that have yet to occur. It comprises four items per subscale that tap each of the following concepts: threat appraisal (i.e., anticipate harm/loss), challenge appraisal (i.e., difficulties may be overcome), centrality (i.e., the importance of the situation), controllable-by-self (i.e., respondents believe they can control the event), and controllable-by-others (i.e., an event is deemed uncontrollable by oneself, but controllable by others). It also contains one item to assess overall stressfulness. The use of multiple items to measure each appraisal enhances reliability. Yet, the instrument may not be suitable for the oncology context because some harm/loss has already been experienced or occurs concurrently with anticipatory stress. For example, people with cancer may perceive “loss of function” due to treatment and experience the “fear of recurrence” at the same time.

Kessler [148] developed the 28-item Cognitive Appraisal of Health Scale to assess appraisals of health-related events. It consists of four subscales that tap Lazarus and Folkman’s [139] appraisal dimensions of threat (6 items), challenge (5 items), harm/loss (8 items), and benign/irrelevant (4 items), as well as secondary appraisals (i.e., whether one has sufficient and appropriate resources to cope effectively; 5 items). Because the items were derived based on theory, as well as interviews with people facing potentially stressful health-related events, the instrument may be suitable to examine cognitive appraisals in the chronic-disease context.

Other measures address specific appraisals. The Mishel Uncertainty of Illness Scale characterizes hospital patients’ experiences of uncertainty [149]. The instrument assesses two aspects of
uncertainty: multi-attributed ambiguity; (i.e., a general factor of ambiguity; 20 items) and unpredictability (i.e., the inability to predict symptomatology and treatment outcomes; 8 items).

Many instruments measure cognitive appraisals. Most are grounded in Lazarus and Folkman’s [139] transactional stress and coping theoretical framework. This limits opportunities to examine appraisals from other perspectives, such as whether a stressor threatens the ability to maintain or abide by one’s cultural values. Although measures that tap specific appraisals, such as uncertainty (e.g., Mishel Uncertainty of Illness Scale), may support such tests, the same appraisal may not always be relevant to every cancer-related stressor. Hence, a promising alternative is to identify and extract unique expressions of the reasons for which people believe that cancer-related events cause them to experience stress (or distress). If the goal of research includes relating stressor appraisals to culturally based values, investigators can then categorize them according to the ways in which these appraisals relate to cultural factors, such as values.

1.3.2 Culture and appraisal

Many psychological theories have posited mechanisms by which culture may influence the appraisal of illness. Lazarus and Folkman [139], for example, asserted that culture offers a system of social rules that helps people to interpret the significance of events. Variations in culturally based social rules produce diverse appraisals that lead people to experience an event as personally meaningful and, therefore, possibly stressful. Other theorists propose that culture shapes the meaning people attribute to somatic symptoms [150,151]. They propose that culture determines whether symptoms are considered to be sufficiently threatening as to elicit distress or merit help-seeking.

Some theories focus on the roles played by values in relation to appraisal. Values reflect the importance people place on various aspects of life such as activities, relationships, possessions, goals, and aspirations [152]. When events threaten highly valued aspects of life, people are likely to construe them as stressors [152]. Events that threaten aspects of life that are not highly valued are generally appraised to be less stressful than those that threaten highly valued aspects. Moreover, Schwartz et al. [153] postulated that values influence the types of worries people experience. They conceptualized “values” as important and desirable life goals that people would like to achieve. People worry when there is a discrepancy between current and desired states. Diverse value priorities (shaped, in part, by culture) likely lead people to interpret the same
situation as threatening to different life goals, which in turn, will elicit diverse worries and concerns [153].

The appraisal of illness-related stressors may be situation-specific. Oyserman et al. [76] proposed that the ways in which people think about and experience situations depend on the types of cultural values they access at the time of the encounter. People can hold both individualist (i.e., emphasizing personal autonomy and freedom) and collectivist (i.e., emphasizing interdependence and social harmony) values and beliefs [76,81,99]. When individualist values are cued at the time people encounter a stressor, their appraisals will be shaped primarily by the individualist cognitive-framework, whereas when collectivist values are activated, they will more likely appraise the stressor from the collectivist framework [76]. In short, the interpretation of a stressor is likely determined by the cultural framework that is activated at the time it occurs.

Theories that link culture and appraisal highlight several key points: (a) people determine the significance of their disease based on their cultural context; (b) different aspects of illness-related situations trigger particular cultural schema (i.e., situation-specific), which in turn, shape the appraisal of situations; and (c) worries or concerns arise when illness-related situations are appraised as disrupting or interfering with aspects of life that are deemed culturally significant and valued.

Although scarce, some evidence supports cross-cultural variations in primary appraisal. Bjorck et al. [154] asked samples of Korean-, Filipino-, and Caucasian-Americans to describe the most stressful situation they had encountered during the preceding week. They then asked the respondents to indicate the extent to which the situation was threatening, challenging, or a loss. Korean-Americans appraised the events as involving more losses than did Caucasians.

Moreover, both Korean- and Filipino-Americans appraised the events as more challenging than Caucasians. The authors speculated that the culture groups’ appraisals were congruent with their cultural values. Specifically, the Korean-Americans were more likely to accept losses because their Eastern worldview values the acceptance of one’s fate, whereas Caucasians were less likely to do so because the Western, individualist worldview encourages people to change (or attempt to change) the situation rather than accepting loss. In addition, the Korean- and Filipino-Americans were more likely than Caucasian-Americans to report challenge appraisals. Because their cultures emphasize compliance with authority (in this case, the researchers), Korean- and
Filipino-Americans may have felt obligated to describe the stressors in positive terms (i.e., a challenge appraisal implies the possibility of gain from the situation). These explanations are plausible, but are based on two assumptions: (a) the Korean- and Filipino-Americans in this study held the Eastern worldview, whereas the Caucasian-Americans held Western values and (b) their appraisals were consistent with their worldviews. Without directly testing both assumptions, we must be cautious in interpreting these findings.

The theories and observations reviewed in this section highlight fundamental principles that must be considered in future investigations of culture and appraisal: (a) culturally based values should be directly examined as explanatory variables; (b) inquiries about appraisals should be situated within the context of specific cancer-related situations; and (c) appraisals should be examined as threats to significant aspects of life, as determined by culturally based values.

1.3.3 Cross-cultural differences in cancer and illness appraisal

Despite growing interest in cross-cultural psychosocial oncology, comparatively few studies examine the role of culture in the appraisal of cancer experience. Moreover, these findings have been inconsistent. For example, among older survivors of breast, prostate, or colorectal cancers, African-Americans were less likely than White Americans to perceive cancer as a stressful life event [10]. Yet, Bourjolly et al. [155] observed no significant differences in primary appraisals of breast cancer between African- and White-Americans. Smith et al. [156] observed that non-Caucasian survivors of non-Hodgkin’s lymphoma were more likely than their Caucasian counterparts to identify positive effects of cancer (i.e., benefit finding).

More consistent findings have been reported in research that used culturally relevant psychological constructs as explanatory variables. For example, Uskul and Hynie [12] tested the hypothesis that how people perceive an illness is associated with their self-construal. They defined illness concerns as whether disease elicited concern about oneself (e.g., “not being able to rely on myself”) or about close others (e.g., “being a burden on people who are close to me”). They also focused on independent (i.e., self-concept as an autonomous entity) versus interdependent (i.e., self-concept based on relationships with others) self-construal. Results indicated that people who primarily maintained independent self-construals were more likely to report a previously experienced illness as a personal concern, whereas those with primarily interdependent self-construals were more likely to report that their conditions elicited social
concern. In another study, Uskul et al. [157] investigated whether the persuasiveness of health-promotion and disease-prevention messages is mediated by the self-regulatory focus (i.e., preference for gain- versus loss-framed messages) in White British and East Asians. White-British respondents found the message to be more persuasive when the health message was gain-framed to fit their predominant health-promotion regulatory focus; the East-Asian respondents found the message to be more convincing when the health message was loss-framed to fit their predominantly health-prevention regulatory focus.

Both of these studies directly measured the underlying cognitive process (i.e., independent-interdependent self-construal and health-promotion versus health-prevention regulatory focus) to which the hypotheses attributed cultural differences in appraisal. These findings support the theoretical perspective that dominant cultural perspectives shape the appraisal of health and illness.

1.4 Summary

Because HNC is common in many countries, health professionals caring for this patient population often interact with people from diverse cultural backgrounds. Culturally based values can shape the ways in which people perceive and experience HNC. Increased understanding of how culture shapes the experience of HNC may help health professionals to deliver more culturally sensitive, patient-centered care [73].

In the next two chapters, I present the research question and hypothesis that guided the current research (Chapter 2), as well as a detailed description of the methods used (Chapter 3).

In Chapter 4, I present the first data-based manuscript, entitled “Measuring Individualism and Collectivism in Adults with Head and Neck Cancer.” This chapter reports the test of factor-structure equivalence of English and Chinese versions of the ICS as completed by Western-born Caucasians and Asian-born Chinese immigrants with HNC. Since the original 4-factor model did not provide a good fit for either group, I proceeded to extract and verify a new measurement model that comprises three factors (i.e., Camaraderie with Co-workers, Commitment to Family, and Competitiveness) using the same data provided by the HNC samples.

Chapter 5 presents the second data-based manuscript, entitled, “Measuring Culturally Based Values in Adults Living with Chronic and Life-Threatening Disease: Validity of a New
Measurement Model for the Individualism-Collectivism Scale in End-Stage Renal Disease, Type 2 Diabetes Mellitus, and Rheumatoid Arthritis.” In this chapter, I disconfirm the original ICS 4-factor model and cross-validate the newly derived 3-factor model in three independent disease samples. The findings confirm the generalizability of the new 3-factor model to other chronically ill populations.

Chapter 6 presents the third data-based manuscript, entitled, “Family Commitment and the Appraisal of Cancer Stressors among Western-Born Caucasian and Chinese Immigrants with Head and Neck Cancer.” In this chapter, I investigate whether people experienced cancer-related events as stressful because they threatened a central cultural value, commitment to one’s family.

In Chapter 7, I discuss the meaning and interpretation of the findings as a whole, and their association with relevant, broader issues. The thesis concludes with general conclusions (Chapter 8) and implications for research and practice (Chapter 9).
Chapter 2
Research aim and hypothesis

The aim of this thesis is to determine whether the appraisals of cancer-related stressors reflect threats to culturally based values among adults with HNC. Specifically, I will test that hypothesis that those who highly endorse a cultural value will report stressor appraisals that reflect threats to that value more frequently than people who do not endorse the value as highly. I will do so in three steps: (a) verify the cultural equivalence of the English and Chinese versions of the ICS; (b) identify appraisals of cancer-related stressors that reflect threats to the cultural values as measured by the ICS; and (c) examine the relations between cultural values and the tendency to report stressor appraisals that reflect threats to them.
Chapter 3  
Methods

This thesis was embedded in a 3-study research program, led by my supervisor, Dr. Gerald Devins, which examined the role of culture in the illness intrusiveness framework [44]. The first two studies developed two instruments: the Cancer-Related Stressor Checklist (CRSC) [41] and the Coping with Cancer Questionnaire. The former measures exposure to common cancer-related stressors, whereas the latter assesses the ways in which people cope with cancer-related stressors.

The third study investigated the moderating effects of age, sex, cultural syndromes, and coping on the psychosocial impact of illness intrusiveness in Western-born Caucasians and Chinese immigrants with HNC. The present thesis complements the third study by examining the influence of cultural syndromes on the appraisal of cancer-related stressors. The participant recruitment strategy and data collection procedures for this thesis were pre-determined by the larger research program. This study was approved by research ethics boards at University Health Network and the University of Toronto.

3.1 Participant recruitment

Study participants for Dr. Devins’s third study were recruited from outpatient HNC clinics at a university-affiliated, tertiary cancer care centre in Toronto, Canada. Inclusion criteria were: age 18 years or older; diagnosed with HNC; undergoing routine medical follow-up following treatment with curative intent; self-identified as Western-born Caucasian or Asian-born Chinese immigrant; and fluent in English, Cantonese, and/or Mandarin. We targeted Western-born Caucasians and Chinese immigrants to maximize the breadth of individualist and collectivist values represented in the study sample. Previous studies have also selected Western-born Caucasians and Chinese immigrants to represent individualist and collectivist cultures, respectively (e.g., [86,100-104]). Oyserman et al. [78] found that Western-born Caucasians tend to be higher in IND and Chinese tend to be higher in COL, which further validates the recruitment strategy.

We employed an arbitrary immigration age cut-off of 12 years to maximize the size of our sampling pool. This threshold allowed us to include Western-born Caucasian immigrants who had spent most of their lives exposed to North-American individualist values, and Chinese
immigrants who spent most of their childhoods exposed to collectivist values. Hence, we defined Western-born Caucasians as Caucasians of European descent who were: (a) born in Canada or the United States or (b) born outside of Canada or United States, but immigrated to Canada before age 12. We defined Chinese immigrants as those of Chinese descent who were born in Asia and immigrated to Canada after age 11. Potential participants self-identified as either Western-born Caucasians or Asian-born Chinese immigrants during recruitment. Responses to ethnic identity and familial immigration history questions on the demographic form substantiated self-reported cultural classification (see Appendix A).

We excluded people who had been diagnosed with HNC eight or more years earlier at the beginning the study to minimize recall biases or other artifacts attributable to memory changes and to avoid major differences in cancer experience given recent advances in treatments.

Sampling was stratified by age (18-34 years, 35-49 years, 50-64 years, and 65 years and older) and sex. This was to ensure sufficient breadth of representation for these variables in the sample to test their hypothesized moderating effects on the psychosocial impact of illness intrusiveness. The stratification created a 16-cell matrix (four age-levels x two sex-levels x two culture groups).

Prospective participants were approached at the HNC clinic waiting room. Research personnel introduced the study, presented the information in the consent form (see Appendix B), answered questions, and solicited consent to participate. People who refused to participate were asked to provide basic information (i.e., sex, age, and culture group) to assess potential selection bias (see Appendix C).

Over a 15-month period, 910 eligible individuals were approached and invited to participate in the study. Of these, 249 (27%) declined to participate. Six hundred and sixty-one individuals (73%) consented, but 122 (18%) withdrew for various reasons (e.g., lack of interest, available time). In all, 539 (59%) respondents were included in the study. Those who refused were significantly older ($M = 62.0; SD = 12.5$) than those who withdrew ($M = 56.0; SD = 14.8$) and those who participated ($M = 56.0; SD = 12.5$), $F(2, 910) = 19.00$, $p < .001$. 


3.2 Materials

The questionnaires used in this thesis were a subset of instruments employed in Dr. Devins’s third study. All were originally developed in English. They were translated into Chinese using standard back-translation protocol [111]. Both language versions were pilot-tested on three Western-born Caucasians and three Chinese immigrants with HNC in December 2005. There was no implementation problem. The following descriptions will focus on the instruments employed in this thesis.

3.2.1 Individualism-Collectivism Scale (ICS)

We obtained the latest version of the ICS from Dr. Harry Triandis at the initiation of the study [H.C. Triandis, personal communication, 2000] (see Appendix D). It is a 32-item scale that taps four subscales (each with eight items): VI, HI, VC, and HC. Respondents indicate their level of agreement or disagreement with each of the 32 statements using a bipolar, 9-point rating scale (1 = strongly disagree; 9 = strongly agree). A mean score is generated for each subscale; higher scores indicate higher endorsement of the cultural syndrome tapped by the subscale. However, the ICS version we employed had not been published to date. I compared this version we employed to its three published predecessors to ensure comparability: the original 32-item version [82], a 29-item version [98], and a 16-item version [91]. I compared item wording and considered the extent to which wording discrepancies affected overall item meaning.

3.2.1.1 Item-content comparison across ICS versions

Table 3 reports the results of the item-content comparisons. The items were organized into three categories within each subscale based on the extent of wording and/or meaning variation between the four ICS versions: (a) no or minimal wording change and no meaning alteration; (b) moderate wording and/or meaning change; and (c) unique items that were not found in other versions.
Table 3. Item discrepancies between four published and unpublished versions of the ICS

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>Items with no or minimal wording discrepancies and no meaning alteration</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Winning is everything.</td>
<td>• Winning is everything.</td>
<td>• Winning is everything.</td>
<td>• Winning is everything.</td>
<td>• Winning is everything.</td>
</tr>
<tr>
<td>• Competition is the law of nature.</td>
<td>• Competition is the law of nature.</td>
<td>• Competition is the law of nature.</td>
<td>• Competition is the law of nature.</td>
<td>• Competition is the law of nature.</td>
</tr>
<tr>
<td>• Without competition, it is not possible to have a good society.</td>
<td>• Without competition, it is not possible to have a good society.</td>
<td>---</td>
<td>---</td>
<td>Without competition it is not possible to have a good society.</td>
</tr>
<tr>
<td>• Some people emphasize winning; I’m not one of them.</td>
<td>• Some people emphasize winning; I’m not one of them.</td>
<td>---</td>
<td>---</td>
<td>Some people emphasize winning; I am not one of them.</td>
</tr>
<tr>
<td>• It annoys me when other people perform better than I do.</td>
<td>• It annoys me when other people perform better than I do.</td>
<td>---</td>
<td>---</td>
<td>It bothers me when other people perform better than I do.</td>
</tr>
<tr>
<td>• It is important that I do my job better than others.</td>
<td>• It is important that I do my job better than others.</td>
<td>---</td>
<td>---</td>
<td>It is important to me that I perform my job better than others.</td>
</tr>
<tr>
<td>• I enjoy working in situations involving competition with others.</td>
<td>• I enjoy working in situations involving competition with others.</td>
<td>---</td>
<td>---</td>
<td>I enjoy working in situations involving competition.</td>
</tr>
<tr>
<td>• When another person does better than I do, I get tense and aroused.</td>
<td>• When another person does better than I do, I get tense and aroused.</td>
<td>---</td>
<td>---</td>
<td>When another person does better than I do, I get tense and feel challenged.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Items with no or minimal wording discrepancies and no meaning alternation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• I often do “my own thing.”</td>
<td>• I often do “my own thing.”</td>
<td>• I often do “my own thing.”</td>
<td>• I often do “my own thing.”</td>
<td>• I often do “my own thing”.</td>
</tr>
<tr>
<td>• I enjoy being unique and different from others in many ways.</td>
<td>• I enjoy being unique and different from others.</td>
<td>---</td>
<td>---</td>
<td>I enjoy being unique (one of a kind) and different from others.</td>
</tr>
<tr>
<td>• I rely on myself most of the time; I rarely rely on others.</td>
<td>• I rely on myself most of the time; I rarely rely on others.</td>
<td>---</td>
<td>---</td>
<td>I rely on myself most of the time; I rarely rely on others.</td>
</tr>
<tr>
<td>• I’d rather depend on myself than on others.</td>
<td>• I’d rather depend on myself than on others.</td>
<td>---</td>
<td>---</td>
<td>I rather rely on myself than on others.</td>
</tr>
<tr>
<td>• My personal identity, independent from others, is very important to me.</td>
<td>• My personal identity, independent of others, is very important to me.</td>
<td>---</td>
<td>---</td>
<td>My personal individuality independent from others is very important to me.</td>
</tr>
<tr>
<td>• I am a unique person, separate from others.</td>
<td>• I am a unique person, separate from others.</td>
<td>---</td>
<td>---</td>
<td>I am a unique (one of a kind) person, different from others.</td>
</tr>
<tr>
<td>----------------------</td>
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<td>--------------------------</td>
<td>------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>• Being a unique individual is important to me.</td>
<td>---</td>
<td>---</td>
<td>• Being a unique (one of a kind) individual is important to me.</td>
<td></td>
</tr>
</tbody>
</table>

**Unique items**

- One should live one’s life independently of others.
- I like my privacy.
- I prefer to be direct and forthright when discussing with people.
- What happens to me is my own doing.
- When I succeed, it is usually because of my abilities.
- My personal individuality is very important to me.

**VC Subscale**

**Items with no or minimal wording discrepancies and no meaning alternation**

- I usually sacrifice my self-interest for the benefit of my group.
- Children should be taught to place duty before pleasure.
- I would do what would please my family, even if I detested that activity.
- We should keep our aging parents with us at home.
- I would sacrifice an activity that I enjoy very much if my family did not approve of it.
- It is important to me that I respect the decisions made by my groups.
- Family members should stick together, no matter what sacrifices are required.
- It is important to me that I respect decisions made by my groups.
- Children should be taught to place duty before pleasure.
- I usually sacrifice my self-interest for the benefit of my group.
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<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>Parents and children must stay together as much as possible.</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>It is my duty to take care of my family, even when I have to sacrifice what I want.</td>
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<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Moderate wording and/or meaning discrepancies</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Before taking a major trip, I consult with most members of my family and many friends.</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>It is important to consult close friends and get their ideas before making a decision.*</td>
</tr>
<tr>
<td>Unique items</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Children should feel honored if their parents receive a distinguished award.</td>
<td>---</td>
<td>---</td>
<td>---</td>
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</tr>
<tr>
<td>• I hate to disagree with others in my group.</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>• Self-sacrifice is a virtue.</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>• It annoys me if I have to sacrifice activities that I enjoy to help others.</td>
<td>---</td>
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</tr>
<tr>
<td>HC Subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Items with no or minimal wording discrepancies and no meaning alternation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• The well-being of my coworkers is important to me.</td>
<td>The well-being of my coworkers is important to me.</td>
<td>The well-being of my coworkers is important to me.</td>
<td>The well-being of my co-workers is important to me.</td>
<td></td>
</tr>
<tr>
<td>• If a coworker gets a prize, I would feel proud.</td>
<td>If a coworker gets a prize, I would feel proud.</td>
<td>If a coworker gets a prize, I would feel proud.</td>
<td>If a co-worker gets a prize, I would feel proud.</td>
<td></td>
</tr>
<tr>
<td>• I like sharing little things with my neighbors.</td>
<td>I like sharing little things with my neighbors.</td>
<td>---</td>
<td>I like sharing little things with my neighbors.</td>
<td></td>
</tr>
<tr>
<td>• If a relative were in financial difficulty, I would help within my means.</td>
<td>If a relative were in financial difficulty, I would help within my means.</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>• It is important to maintain harmony within my group.</td>
<td>It is important to maintain harmony within my group.</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>• I feel good when I cooperate with others.</td>
<td>---</td>
<td>I feel good when I cooperate with others.</td>
<td>---</td>
<td></td>
</tr>
</tbody>
</table>

*Note: The asterisk (*) indicates a slight wording difference.
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>• To me, pleasure is spending time with others.</td>
<td>---</td>
<td>• To me, pleasure is spending time with others.</td>
<td>• To me, happiness is sharing time with others.</td>
</tr>
<tr>
<td>• My happiness depends very much on the happiness of those around me.</td>
<td>---</td>
<td>---</td>
<td>• My happiness depends very much on the happiness of those around me.</td>
</tr>
<tr>
<td><strong>Unique item</strong></td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>• It is important to consult close friends and get their ideas before making a decision.*</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
</tbody>
</table>

Note: Wordings that varied across the versions were underlined for ease of comparison.
Note: “---” reflects that a particular ICS version does not have a comparable form for an item
* This item was grouped under the HC subscale in the 1996 version, but was listed under the VC subscale in the 2000 version.

For the VI subscale, all eight items have either no or minimal wording discrepancies (e.g., “I do my job” versus “I perform my job”), which did not alter their meaning. Thus, the VI items were considered to be equivalent across the four versions.

For the HI subscale, seven items were deemed to have no or minimal wording discrepancies; five of them appeared starting in the 1996 version. The 1995 version has five unique items and the 2000 version has one unique HI item. Overall, the HI subscale in the 2000 version was deemed to be mostly consistent with the 1996 and 1998 versions, and the 1995 HI subscale is not comparable with the others.

For the VC subscale, nine items had no or minimal wording discrepancies across versions. However, three of these items appeared only in the 1995 and 1996 versions, and three others were found only in the 1998 and 2000 versions. Wording and meaning deviated moderately for one item. Although both conveyed the idea of soliciting close friends’ and loved ones’ advice before making decisions, the 1995 item, “Before taking a major trip, I consult with most members of my family and many friends,” is a specific example of the idea expressed in its 2000 counterpart, “It is important to consult close friends and get their ideas before making a decision.” In terms of unique items, two were found in the 1995 version, two in the 1996 version,
and one in the 2000 version. The VC subscale in the 2000 version is the most comparable to the 1998 version because the items are identical in these versions.

For the HC subscale, eight items were judged to have no or minimal wording discrepancies. However, one of these appeared only in the 1995 and 2000 versions. The 1996 HC item, “It is important to consult close friends and get their ideas before making a decision,” was listed under the VC subscale in the 2000 version. As a result, this item was categorized as a “unique item.” The 2000 version is most comparable to the 1995 and 1998 versions since all the common items were deemed to have no or minimal discrepancies.

Overall, the comparison of ICS item content revealed a great number of item or content variations in the HI and VC subscales across the three published versions, but the authors of each version did not provide any rationale for these alterations. Items in the 2000 version that we employed appeared to be the most consistent with the corresponding 16 items published by Triandis and Gelfand [91]. To ensure that the results presented in this thesis can be compared meaningfully with existing published work, I only used data from the same 16 items that comprise the 1998 version in subsequent analyses.

3.2.1.2 Verification of Chinese translation of the ICS

Dr. Devins’s research team translated the ICS into Chinese for a previous study (see Appendix D) using standard back-translation procedures [111]. Though it was deemed adequate initially, I noted some translation inaccuracies. Thus, I initiated an independent evaluation of the Chinese translation of the ICS. The bilingual team members consisted of a professional translator, a nursing professor, and me. None of these bilingual members were involved in the original translation. First, we independently reviewed the translation and identified all items that were inaccurately translated. We subsequently compared our findings and reached consensus about the extent of inaccuracy. The bilingual team determined that four of the 16 items were not translated precisely. The team back-translated the four questionable items to determine the extent of discrepancy. Table 4 summarizes the back-translation and bilingual team’s decisions.

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2 Both the 16-item 1998 version and the 2000 version I employed used a 9-point rating scale, whereas the original 1995 scale used a 7-point scale. This further supports my decision to employ the same items as those in the 1998 version.
Table 4. Back-translation comparison of the Chinese ICS items that were deemed imprecisely translated by bilingual research team members

<table>
<thead>
<tr>
<th>Subscale</th>
<th>English original</th>
<th>Original Chinese translation</th>
<th>Back-translation</th>
<th>Final decision</th>
</tr>
</thead>
<tbody>
<tr>
<td>HC</td>
<td>• The well-being of my coworkers is important to me.</td>
<td>• 我的同僚是否身心安好對我來說是重要的。</td>
<td>• Whether my co-workers are physically and emotionally well is important to me.</td>
<td>• No significant difference in meaning; use as is</td>
</tr>
<tr>
<td>HC</td>
<td>• If a coworker gets a prize, I would feel proud.</td>
<td>• 如我的同僚獲獎，我會感到驕傲。</td>
<td>• If my co-worker gets a prize, I would feel proud.&quot;</td>
<td>• No significant difference in meaning; use as is</td>
</tr>
<tr>
<td>HI</td>
<td>• I often do “my own thing.”</td>
<td>• 我時常依自己的方式做事。</td>
<td>• I often do things my way.</td>
<td>• Significant difference in meaning; but reflect similar concept; use as is</td>
</tr>
<tr>
<td>HI</td>
<td>• My personal individuality independent from others is very important to me.</td>
<td>• 對我來說，我個人的個性獨立於其他人是重要的。</td>
<td>• To me, my own personality independent from others is important.</td>
<td>• Significant difference in meaning; but reflect similar concept; use as is</td>
</tr>
</tbody>
</table>

*驕傲* means “proud”, but also has an added meaning of “arrogance”; traditionally the term is often referred as a negative personal trait. However, the contemporary use the term, 驕傲, does not carry the connotation of arrogance.

Back-translation of the two imprecisely translated HC items revealed that they tapped similar concepts despite minor differences. Thus, the bilingual team judged the English and Chinese versions of these HC items to be comparable. The two HI items, however, differed more substantially in wording and meaning between the language versions. Discussion with other research-team members led the bilingual team to conclude that the item, “I often do ‘my own thing,’” and its back-translated counterpart, “I often do things my way,” tapped a common idea of acting on the basis of one’s own judgment. For the item, “My personal individuality independent from others is important to me,” and its back-translated version, “My own personality independent from others is important to me,” the team concluded that both phrases emphasize the value of unique qualities that set one apart from others. Although the team did not consider these items to be identical, it is reasonable to suggest that these English and Chinese phrasings tap the same underlying concept [158]. Thus, data collected using the items will be treated as equivalent for the purposes of data analysis.
3.2.1.3 Comparison of two versions of the Chinese ICS

In the second data-based manuscript to be presented (see Chapter 5), I report findings bearing on the measurement invariance of the ICS using data from Western-born Caucasians and Chinese immigrants affected by other chronic diseases: end-stage renal disease (ESRD) and Type 2 diabetes mellitus (DM). Because these data were collected for an earlier study [Devins et al., unpublished data], a slightly different Chinese version of the ICS was employed. Thus, the same bilingual team in this study compared the two Chinese ICS versions to determine the extent of translation comparability. Table 5 presents the discrepant items, their back-translations, and the bilingual team’s decisions.

Table 5. The Chinese ICS items that are discrepant between the versions used by those with HNC and those with ESRD or Type 2 DM

<table>
<thead>
<tr>
<th>English original (subscale)</th>
<th>HNC Chinese translation</th>
<th>ESRD-Type 2 DM Chinese translation</th>
<th>Back-translation of discrepant sections</th>
<th>Comparison result</th>
</tr>
</thead>
<tbody>
<tr>
<td>• My personal individuality independent from others is very important to me. (HI)</td>
<td>• 我個人的個性獨立於其他人是重要的。</td>
<td>• 我重視個人的獨立身份，有別於他人。</td>
<td>• 個人的個性: own personality</td>
<td>• Both phrases tap into the idea of “who am I?”</td>
</tr>
<tr>
<td>• Family members should stick together, no matter what sacrifices are required. (VC)</td>
<td>• 一家人應團結一心，無論需要作出任何犧牲。</td>
<td>• 家庭成員應要共患難，無論要作出任何犧牲。</td>
<td>• 團結一心: together as one • 共患難: be together through tough times</td>
<td>• Both phrases emphasize the importance of the family acting as a unity.</td>
</tr>
<tr>
<td>• The well-being of my coworkers is important to me. (HC)</td>
<td>• 我的同僚是否身心安好對我來說是重要的。</td>
<td>• 同事們的健康 / 福利對我來說是很重要的。</td>
<td>• 身心安好: physical and emotional well-being • 健康/福利: health or welfare</td>
<td>• Both phrases focus on the overall wellness of others.</td>
</tr>
<tr>
<td>• If a coworker gets a prize, I would feel proud. (HC)</td>
<td>• 如我的同僚獲獎，我會感到驕傲。</td>
<td>• 若有一位同事獲獎，我會以此為榮。</td>
<td>• 驕傲: be proud • 以此為榮: be proud because of this</td>
<td>• Both phrases underscore being full of pride due to other’s accomplishment.</td>
</tr>
</tbody>
</table>

Note: The main discrepant Chinese phrases between the two versions were underlined for ease of comparison.

*驕傲 also has a traditional meaning of “arrogance,” considered as a negative personal trait. However, the contemporary use the term, 驕傲, does not carry the connotation of arrogance.
Our comparison of the Chinese versions of the ICS identified four items with meaning discrepancies. Because they were judged to tap similar constructs, the bilingual team deemed the overall meanings of the discrepant phrases to be comparable. Therefore, data collected using the two Chinese versions of the ICS were treated as equivalent in subsequent analyses.

3.2.2 Cancer-Related Stressor Checklist (CRSC)

The CRSC assesses exposures to common cancer- and treatment-related stressors. The CRSC is described as a 24-item instrument in a recent paper [41]. It was refined after the work reported in this thesis was completed. Thus, I will report data collected using an earlier version of the CRSC. The number and categorization of CRSC items differ slightly from the published version; however, the corresponding items’ content and response format are identical.

The 40 CRSC stressor items are organized into eight categories: disease and treatment (four items); existential threats (four items); interference with activities (four items); interpersonal issues (five items); lack of information (four items); stigma (three items); subjective distress (seven items); and uncertainty (nine items; see Table 6). Using a yes/no format, respondents indicate whether they experienced each stressor at any point during their cancer experience. The total number of stressors endorsed reflects burden of stress.

I added an open-ended question (i.e., “What is the most stressful part about this situation for you?”) to identify appraisals of CRSC stressors. It asks respondents to indicate the reason(s) why respondents experienced the situation as stressful to them. To minimize respondent burden, I only employed the open-ended question for the three most commonly experienced stressors from each of the eight CRSC categories, identified based on the findings of the second study in the overall research program. These 24 stressors were divided into three parallel sets of eight such that each set included one of the three most frequently endorsed stressors within each category (see superscripts in Table 6). The resulting three versions of the questionnaire provided parallel versions with which to assess causes of stress in cancer stressors. Respondents were randomly assigned to one of the three CRSC versions, with the qualification that equal numbers of each version be administered.
Table 6. The 40 CRSC items and the categories in which they were categorized

<table>
<thead>
<tr>
<th>CRSC category</th>
<th>CRSC stressor item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease and treatment</td>
<td>• I feel weak and tired ¹</td>
</tr>
<tr>
<td></td>
<td>• I need prompt medical attention ²</td>
</tr>
<tr>
<td></td>
<td>• I feel sick because of symptoms or side effects ³</td>
</tr>
<tr>
<td></td>
<td>• My cancer gets worse</td>
</tr>
<tr>
<td>Existential issues</td>
<td>• I realize that I may die ¹</td>
</tr>
<tr>
<td></td>
<td>• I feel all alone because of my disease ²</td>
</tr>
<tr>
<td></td>
<td>• I wonder whether life is worth living ³</td>
</tr>
<tr>
<td></td>
<td>• I ask myself if there’s still any meaning in life</td>
</tr>
<tr>
<td>Interference with activities</td>
<td>• I do not have enough strength or stamina to do the things I want to do ¹</td>
</tr>
<tr>
<td></td>
<td>• My disease and treatment make it difficult to do the things that matter most to me in life ²</td>
</tr>
<tr>
<td></td>
<td>• I realize that I have lost important opportunities because of my disease ³</td>
</tr>
<tr>
<td></td>
<td>• I experience sex-related problems because of my illness or its treatment</td>
</tr>
<tr>
<td>Interpersonal issues</td>
<td>• People worry about me because I have cancer ¹</td>
</tr>
<tr>
<td></td>
<td>• People ask me questions about my disease or treatment ²</td>
</tr>
<tr>
<td></td>
<td>• I need emotional support from friends and family ³</td>
</tr>
<tr>
<td></td>
<td>• I need help from other people</td>
</tr>
<tr>
<td></td>
<td>• Conflicts arise with family or friends</td>
</tr>
<tr>
<td>Lack of information</td>
<td>• I need to speak to my doctor(s) or other healthcare provider(s) ¹</td>
</tr>
<tr>
<td></td>
<td>• I don’t have as much information about cancer treatment as I need or want ²</td>
</tr>
<tr>
<td></td>
<td>• I don’t understand instructions or advise given by my doctor or other healthcare provider ³</td>
</tr>
<tr>
<td></td>
<td>• I don’t understand my treatment</td>
</tr>
<tr>
<td>Stigma</td>
<td>• People don’t know how to respond because I have cancer ¹</td>
</tr>
<tr>
<td></td>
<td>• People avoid me because I have cancer ²</td>
</tr>
<tr>
<td></td>
<td>• I feel people look down on me because I have cancer ³</td>
</tr>
<tr>
<td>Subjective distress</td>
<td>• I feel anxious or depressed ¹</td>
</tr>
<tr>
<td></td>
<td>• I need emotional release ²</td>
</tr>
<tr>
<td></td>
<td>• I feel frustrated about my ill health ³</td>
</tr>
<tr>
<td></td>
<td>• I start to feel sorry for myself</td>
</tr>
<tr>
<td></td>
<td>• I feel intense stress</td>
</tr>
<tr>
<td></td>
<td>• I feel discouraged</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>• I wonder whether my disease will get worse or recur ¹</td>
</tr>
<tr>
<td></td>
<td>• I am anxious about medical test results ²</td>
</tr>
</tbody>
</table>
### CRSC category

<table>
<thead>
<tr>
<th>CRSC stressor item</th>
</tr>
</thead>
<tbody>
<tr>
<td>• I realize that I cannot control this disease $^3$</td>
</tr>
<tr>
<td>• I don’t know what the future may hold for me</td>
</tr>
<tr>
<td>• I must make decisions about my treatment</td>
</tr>
<tr>
<td>• I think about my family’s welfare after I am gone</td>
</tr>
<tr>
<td>• I cannot control the things that are important to me in life</td>
</tr>
<tr>
<td>• I wonder whether I will live long enough to benefit from new treatments or cures</td>
</tr>
<tr>
<td>• I have doubts about my doctor’s treatment of my cancer</td>
</tr>
<tr>
<td>• I feel inadequate as a person</td>
</tr>
</tbody>
</table>

*Note: Superscripts represent one of the three CRSC versions to which an item was assigned.*

Appendix E provides an example of the questionnaire. The eight CRSC stressors to which the open-ended question was added are framed in a box. The two specific questions relevant to this thesis are: Part (a), “Have you experienced this?” determines whether the respondent was ever exposed to the stressor and Part (c) is the open-ended question to document the respondent’s reported causes of stress.

#### 3.2.3 Memorial Sloan-Kettering Symptom Assessment Scale (MSAS)

The MSAS [159] is a self-report symptom checklist that documents current cancer-symptom burden (see Appendix F). It asks respondents to identify all of the symptoms they experienced during the preceding week. The total number of symptoms experienced indicates the current physical burden of disease. We employed a modified version of the MSAS. The 27-item modified scale was initially developed to tap common physical symptoms (e.g., pain, drowsiness, mouth sores) among people with hematologic cancers treated by bone-marrow transplantation [160]. Items that overlap with emotional or functional outcomes were excluded to prevent measurement redundancy when used to examine subjective well-being outcomes.

#### 3.2.4 Demographic, clinical, and treatment information

Demographic information was collected using a self-report form (see Appendix A). Information related to respondents’ disease and treatment was obtained from Ontario Cancer Registry, a government-funded database about people diagnosed with and/or deceased due to cancer in Ontario [161]. The following information was used in this thesis: date of diagnosis, cancer stage,
first diagnosis or recurrence, and types of treatment received. Duration of disease was calculated based on the dates of diagnosis and interview.

3.3 Data collection procedures

Research personnel contacted consenting volunteers to schedule an in-person interview. Interviews were conducted either at the cancer center or at the respondent’s home. Trained interviewers (including myself) conducted the interviews in English, Cantonese, or Mandarin, according to respondents’ preference. At the beginning of each interview, the interviewer explained the study procedures, answered questions, and provided the respondent with a copy of the questionnaire package to which they could refer. The interviewer then read questions and response alternatives aloud and recorded the participant’s responses. Interviews took 1.5 - 2.5 hours to complete. At the conclusion, each respondent received monetary compensation ($20) in the form of a cash voucher, redeemable at the cancer center.

Data collection forms were created using TELEform software [162] to permit optical-scanning data entry. Responses to multiple-choice questions were scanned and entered into an electronic database; verbal responses to open-ended questions were audio-recorded digitally and later transcribed verbatim. When a respondent refused to be audio-taped, the interviewer recorded the responses on paper and later entered them manually.

Interviewers were also trained in transcription. For each English interview, the audio-taped portion was transcribed by the interviewer who conducted the interview. Another interviewer independently verified the transcript by comparing it to the audiotape and corrected the discrepancies.

Cantonese and Mandarin interviews were transcribed in Chinese, following similar procedure as English interviews. Once verified, the bilingual Research Coordinator, who was also a professional translator, translated the Chinese transcripts. I then independently verified the translations by comparing the English transcripts and their Chinese translation. Substantive variations in translation were discussed between and resolved by the Research Coordinator and myself. NVivo 8.0 software [163] was used to organize qualitative data.
3.4 Manuscript-specific methods and analytic strategies

The study findings for this thesis will be presented in three manuscripts that have been prepared for independent publication. Although each manuscript includes a section that describes the research methods employed, the following sections elaborate on these. In addition, the following section provides insights into the strategies that informed the statistical analyses reported in each data-based paper.

3.4.1 Methods employed in manuscript, “Measuring Individualism and Collectivism in Adults with Head and Neck Cancer”

The ICS has been widely used in cultural research, but questions persist about its psychometric adequacy. In this manuscript (see Chapter 4), I evaluated the cultural equivalence of English and Chinese versions of the ICS in Western-born Caucasians and Chinese immigrants with HNC. The findings indicated that the original 4-factor measurement model did not provide a good fit to the data. I, therefore, derived and verified a new measurement model based on observations in the HNC samples.

3.4.1.1 Participants

This paper included most of the respondents recruited for Dr. Devins’s study. Participant recruitment was described earlier (see Section 3.1). Of the 539 people recruited, 418 (78%) were Western-born Caucasians and 121 (22%) were Chinese immigrants. Within this sample, 403 (97%) Western-born Caucasians and 119 (98%) Chinese immigrants provided complete ICS data. I included only respondents who provided complete data in this paper given that so few people had missing data.

3.4.1.2 Statistical methods

3.4.1.2.1 Measurement invariance of the ICS measurement model

I conducted confirmatory factor analysis (CFA) to determine whether the hypothesized 4-factor ICS model (i.e., VI, HI, VC, and HC) achieved measurement invariance across the responses provided by Western-born Caucasians and Chinese immigrants with HNC. Measurement invariance refers to the extent to which scale items represent latent factors in the same ways across respondent groups [114]. It is an important psychometric characteristic to establish before
proceeding to multi-group factor-score comparisons. When a factor structure is not equivalent across groups, group differences in factor scores may be attributed to between-group differences in factor-structure elements, rather than reflecting actual between-group differences [164].

Tabachnick and Fidell [113] recommend a minimum ratio of 5:1 (participants to items) for CFA. Our sample sizes more than satisfied this criterion: the ratio was 26:1 for Western-born Caucasians and 8:1 for Chinese immigrants.

I tested the original, hypothesized 4-factor model [91]. I also tested two published alternative models: (a) a 3-factor model, which includes VI, HI, and an aggregated COL subscale (combining VC and HC subscales) [82]; and (b) a 2-factor model, which aggregates the IND (combining VI and HI) and COL subscales [80].

I used EQS for Windows (version 6.1) to conduct the CFAs. The first step in assessing measurement invariance is to establish factor-structure equivalence with each group’s data [164]. If the model fits well with data from various samples independently, it is appropriate to proceed to test measurement invariance across groups using multi-sample CFA (MSCFA). Because CFA results can be compromised when data are distributed non-normally, I examined robust ($\chi^2/df$) fit indices, which adjust for this problem [165]. I evaluated model fit using the following goodness-of-fit criteria [113,165]: Satorra-Bentler (SB) scaled $\chi^2/df$ ratio, non-normed fit index (NNFI$^{\text{rob}}$), comparative fit index (CFI$^{\text{rob}}$), adjusted goodness-of-fit index (AGFI), standardized root mean squared residual (SRMR), and root mean-square error of approximation (RMSEA$^{\text{rob}}$). I adopted the following recommended criteria for “excellent” model fit [113,165]: SB $\chi^2/df$ ratio $< 2.0$, NNFI$^{\text{rob}}$, CFI$^{\text{rob}}$, and AGFI $> .90$, SRMR and RMSEA$^{\text{rob}}$ $\leq .08$. Others have suggested that a $\chi^2/df$ ratio $< 3$ indicates acceptable fit [166,167].

For each latent factor, a specific factor loading must be fixed so that others are free to be estimated [165]. To determine which factor loading should be fixed, I used exploratory factor analysis (EFA) on the entire HNC sample to identify the item with the highest factor loading for each latent factor (i.e., the item that contributed most variance to the factor and, therefore, contributed most importantly to the latent construct represented by the factor). The same factor structure, including the identical fixed factor loadings, was tested in the CFAs on data from Western-born Caucasians and Chinese immigrants.
3.4.1.2.2 Exploratory factor analysis

In the CFA, I established that the existing ICS measurement model did not fit the data collected from Western-born Caucasians and Chinese immigrants with HNC. This means that the published subscales did not measure VERT-HOR IND and COL as intended in these samples. A common factor structure is essential to compare cultural syndromes directly between culture groups. Hence, I conducted exploratory factor analyses (EFAs) to inform a new measurement model that would reflect the responses of both Western-born Caucasians and Chinese immigrants with HNC equally.

EFAs identify latent factors that explain why certain items, or manifested variables, relate more with one another in the data. The more commonly used EFA method, principal component analysis, is less suited for this purpose because its data reduction approach does not take into account latent factor structures [168-170]. Due to skewed data (i.e., skewness > 2) [171], I used principal factor extraction, a type of EFA [168]. I applied both oblique and orthogonal rotations to determine whether the new factors were correlated or statistically independent, respectively [168,170]. Since both rotations produced the same factor solution, I will present factor solutions based on the orthogonal rotation to allow for a more distinct conceptualization of factors.

I conducted separate EFAs were conducted for Western-born Caucasians and Chinese immigrants to ensure that I did not inadvertently combine data with different underlying factor structures. If the separate EFAs generated similar factor structures, it justifies combining the data to extract a common factor structure for the data from both Western-born Caucasians and Chinese immigrants.

I used scree plots, instead of the eigenvalue greater-than-1 criterion, to determine the number of factors to retain [170]. The latter tends to result in over-retention of factors [172]. An item was retained as representative of a factor when (a) it loaded uniquely onto a factor and (b) its factor loading was greater than .32 [113,169]. When an item loaded onto more than one factor and the loadings were greater than .50, the item was not retained to ensure distinct factors [170].

As will become evident in Chapter 4, the measurement models extracted for the Western-born Caucasian and Chinese immigrant datasets were different. I, therefore, adopted a novel approach to identify a common factor model and, thus, allow for subsequent comparison of cultural values
between the groups: I created new subscales by selecting items that loaded on a single factor in each of the Western-born Caucasian and Chinese immigrant datasets. For example, if two items that were loaded onto one factor in the Caucasian data were also loaded onto a single factor in the Chinese data, then I would select them as a measure of a new latent factor. New label and conceptual definition were assigned to the new factors based on the theme that the items reflect [113]. Chapter 4 reports the exact process in which the new factor model was derived.

3.4.1.2.3 Measurement invariance of the newly proposed model

I conducted a second series of CFAs to verify the measurement invariance of the newly extracted model. Although it is more common to confirm model fit using an independent sample, such data were not available. Some authorities maintain that it is reasonable to employ CFA to test the goodness-of-fit of an EFA-extracted model using the same data [173]. They reason that the model is unlikely to provide a good fit in other independent samples when the CFA result does not corroborate the corresponding EFA finding. Hence, I conducted an initial validation of the new EFA-derived model by testing its measurement invariance using the same HNC Western-born Caucasian and Chinese immigrant data from which it was derived.

I began by testing whether the newly derived measurement model provided a good fit to each of the HNC Western-born Caucasian and Chinese immigrant datasets separately. I applied the same CFA procedure and goodness-of-fit criteria as described earlier. Because I established independent model fit with data from each group, I proceeded to conduct a MSCFA. This entails a rigorous, multi-step evaluation of model fit by conducting simultaneous tests in both Western-born Caucasian and Chinese immigrant groups. I employed the Means and Covariance Structure (MACS) analysis [164] to achieve this. The MACS approach tests increasingly rigorous, hierarchical levels of invariance [115,164] (see Table 7).

The established level of invariance indicates the extent to which valid interpretations and syntheses of test scores can be made across respondent groups. When an instrument demonstrates strong or strict invariance, it is possible to conduct valid comparisons of mean latent-scores across groups [164,174,175]. When an instrument is characterized by weak invariance, it is valid to compare hypothesized associations between the mean latent-scores and other variables across groups [114,176].
Table 7. Hierarchical levels of invariance testing in MACS analysis

<table>
<thead>
<tr>
<th>Invariance level (from least to most stringent)</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Configural invariance</td>
<td>• Basic factor structure is equivalent across groups</td>
</tr>
<tr>
<td>Weak invariance</td>
<td>• Factor loadings are equivalent across groups (assess only once configural invariance has been established)</td>
</tr>
<tr>
<td>Strong invariance</td>
<td>• Item intercepts are equivalent across groups (assess only after weak invariance has been established)</td>
</tr>
<tr>
<td>Strict invariance</td>
<td>• Items error variances are equivalent across groups (assess only if strong invariance has been established)</td>
</tr>
</tbody>
</table>

To determine the level of invariance, I sequentially added equality constraints (i.e., a set of parameters that is defined as equivalent across groups; one set for each level of invariance) to the model after establishing configural invariance [165]. Invariance is supported when (a) a $\chi^2$-difference test shows non-significant change (i.e., $p > .05$) in $\chi^2$ between the current model with the equality constraint and the preceding one that does not include it [164] and (b) the model satisfies goodness-of-fit criteria [113,165]. The model must demonstrate cross-group invariance at one step before it is valid to test the next, more rigorous level of invariance (i.e., the models are hierarchically nested).

If the model does not initially demonstrate invariance at a given level, post-hoc model modifications can be considered. These adjustments can be incorporated, in moderation and with the theoretical framework in mind, to improve a model’s goodness of fit. I performed Lagrange Multiplier (LM) tests to identify possible post-hoc model modification. Some scholars have argued against this practice because it alters a-priori specified parameters (e.g., [177,178]). Others, however, have acknowledged the difficulties in achieving perfect models a priori and, therefore, propose that limited parameter adjustments offer a reasonable compromise in articulating a theoretically sound model [179,180].

3.4.2 Methods employed in manuscript, “Measuring Culturally Based Values in Adults Living with Chronic and Life-Threatening Disease: Validity of a New Measurement Model for the Individualism-Collectivism Scale in End-Stage Renal Disease, Type 2 Diabetes Mellitus, and Rheumatoid Arthritis”

In the manuscript, to be reported in Chapter 4, I demonstrated that the original ICS 4-factor structure does not provide a good fit to the data from Western-born Caucasians and Chinese
immigrants with HNC. I, therefore, extracted and validated a new, alternative measurement model using data from the HNC samples. The new model entails three subscales that tap more specific variables that conceptually relate to IND (i.e., Competitiveness) or COL (i.e., Camaraderie with Co-workers and Commitment to Family).

In the manuscript reported in Chapter 5, I seek: (a) to confirm the measurement invariance of the original 4-factor ICS measurement-model in three independent, multi-cultural, chronic-disease groups: Western-born Caucasians and Chinese immigrants with ESRD or Type 2 DM, and English-speakers with rheumatoid arthritis (RA); and (b) to use MSCFA to cross-validate the new 3-factor model in these samples.

3.4.2.1 Participants

I used ICS data collected from three independent samples who participated two previous studies, led by Dr. Devins: (a) self-identified Western-born Caucasians and Chinese immigrants with ESRD ($n = 261$) or Type 2 DM ($n = 259$) [Devins et al., unpublished data] and (b) English-speakers with RA ($n = 106$) [132]. Both studies tested the illness intrusiveness theoretical framework. The diversity that characterizes these three samples introduces considerable heterogeneity, which, I believe, allows for a stringent test of the newly derived 3-factor ICS measurement model’s reproducibility. If the new 3-factor model can be cross-validated in these samples, it would be reasonable to conclude that the model is generalizable to populations beyond those with HNC.

3.4.2.1.1 ESRD and Type 2 DM samples

As in the manuscript, “Measuring Individualism and Collectivism in Adults with Head and Neck Cancer,” only respondents who provided complete ICS data were included in statistical analyses. In the ESRD and Type 2 DM samples, 206 (79%) and 223 (86%) respondents provided complete data, respectively. Those who provided complete data were younger ($M = 59.68; SD = 11.41$) than those with missing data ($M = 63.34; SD = 11.89$), $t(127) = 2.69, p = .008$. More respondents with missing data (23%) were not working for pay than those who provided complete data (3%), $\chi^2(1) = 27.72, p < .001$.

Because too few Western-born Caucasians with Type 2 DM ($n = 101$) and Chinese immigrants with ESRD ($n = 82$) were available for separate CFAs (i.e., < 5:1 ratio of respondents to items as
recommended [113]), I pooled the data to achieve sufficient sample size. I combined the data from respondents with ESRD or Type 2 DM within each culture group (i.e., Western-born Caucasians with ESRD or Type 2 DM and Chinese immigrants with ESRD or Type 2 DM) because the study objective was to compare cultural syndromes across culture groups, rather than across disease groups. The final sample size for each culture group was 185 ESRD-Type 2 DM Western-born Caucasians and 195 ESRD-Type 2 DM Chinese immigrants.

Some differences between Western-born Caucasians and Chinese immigrants with ESRD or Type 2 DM should be noted. Among Western-born Caucasians, a higher percentage of people with Type 2 DM completed primary, undergraduate, and graduate/professional education than those with ESRD, $\chi^2(5) = 13.51, p = .019$. More Western-born Caucasians with Type 2 DM reported having annual household incomes greater than $75,000 than Western-born Caucasians with ESRD, $\chi^2(5) = 26.98, p < .001$. In both culture groups, more people with Type 2 DM were working for pay as compared to ESRD, $\chi^2(1) = 32.50, p < .001$ (Western-born Caucasians); $\chi^2(1) = 7.60, p = .006$ (Chinese immigrants). These differences are likely attributable to disease-specific characteristics, rather than reflections of systematic differences, between the “types of people” who develop these conditions. For example, as compared to Type 2 DM, people treated for ESRD (a) require more intrusive medical treatment (e.g., primarily dietary and activity management in Type 2 DM versus weekly maintenance dialysis in ESRD in addition to dietary management) and (b) typically experience more severe symptoms (e.g., fatigue and cognitive problems) that interfere with work life [181]. Among the Chinese immigrants, times since diagnosis was longer for people with Type 2 DM as compared to ESRD, $t(193) = 2.95, p = .004$. These group differences should be borne in mind in interpreting the results.

3.4.2.1.2 RA sample

The RA sample included 102 (96%) respondents who provided complete ICS data. The included respondents was older ($M = 69.00; SD = 7.35$) than excluded respondents ($M = 56.76; SD = 13.87$), $t(4) = 3.12, p = .037$. The sample consisted of English-speakers born primarily in Canada or the US ($n = 68, 68\%$), and most ($n = 95, 93\%$) reported their ethnicity as either Canadian or a mix of Canadian and European descent.
3.4.2.2 Statistical methods

3.4.2.2.1 Evaluating model fit of the original 4-factor model in ESRD-Type 2 DM and RA samples

I tested the original 4-factor model (i.e., VI, HI, VC, and HC) [91] and two published, alternative models: (a) a 3-factor model, which includes VI, HI, and an aggregated COL subscale [82]; and (b) a 2-factor model, which aggregates the IND and COL subscales [80], with the data obtained from ESRD-Type 2 DM Western-born Caucasians, ESRD-Type 2 DM Chinese immigrants, and English-speakers with RA. I adopted the same procedure and goodness-of-fit criteria as in the CFAs that examined HNC data (see Section 3.4.1.2.1). If any of the ICS models provided a good fit to the data from the three samples independently, the strategy would be to proceed to test the measurement invariance of that model across all three groups simultaneously using the more rigorous test of MSCFA, as outlined in section 3.4.1.2.3.

3.4.2.2.2 Testing for measurement invariance of new 3-factor model

The primary purpose of this set of CFAs is to test the measurement invariance of the new 3-factor model. I first tested the fit of the proposed 3-factor model separately in each of the three groups: Western-born Caucasians with ESRD or Type 2 DM, Chinese immigrants with ESRD or Type 2 DM, and English-speakers with RA. After establishing that the models fit well with data from each group, I proceeded to perform a MSCFA, a rigorous, multi-step evaluation of model fit by applying it simultaneously to the data from all three groups. Successful cross-validation of the hypothesized measurement model provides evidence of its generalizability. I employed the same MSCFA protocol and goodness-of-fit criteria in this paper as I did in the previous MSCFA (see Section 3.4.1.2.3).

3.4.3 Methods employed in manuscript, “Family Commitment and the Appraisal of Cancer Stressors among Western-Born Caucasian and Asian-Born Chinese Adults with Head and Neck Cancer”

In this manuscript, I investigated whether people’s cultural values shape their appraisals of cancer-related stressors. I did so by testing the hypothesis that people experience cancer-related events as stressful when the events threaten centrally held cultural values.
3.4.3.1 Participants

The larger study in which this study was embedded recruited 539 respondents. Post-hoc calculations (based on $\alpha = .05$, and $d = .03$ to achieve power = .90) estimated that a minimum of 240 respondents were required to ensure adequate statistical power to test the association between cultural values and appraisals of cancer-related stressors [182]. Rather than randomly selecting the subsample, I purposefully selected this sample for two reasons. First, because the three CRSC versions I employed asked about different, but comparable, sets of cancer stressors (see Section 3.2.2), I needed to ensure that the entire set of 24 stressors would be represented equally in subsequent analyses. Thus, equal numbers of transcripts ($n = 80$) from each of the three CRSC versions were selected. Second, some respondents did not report a cause of stress for every stressor. This may be due to recall difficulties or a stressor not being experienced as stressful. To ensure that I would obtain as much qualitative data as possible, I trained an independent research assistant to screen the transcripts and select the 240 transcripts that met the following a-priori criteria for analysis (see Figure 1): a transcript would be selected if (a) at least one stressor appraisal was identified from each of the eight open-ended, stressor appraisal responses; (b) if the first criterion could not generate 80 transcripts from each version, then transcripts that had, at least, one stressor appraisal for seven of the eight stressor appraisal responses would be selected; (c) if the first and second criteria could not generate 80 transcripts from each version, then transcripts with, at least, one stressor appraisal for six of the eight stressor appraisal responses would be selected; and (d) if the first three criteria could not generate sufficient transcripts to achieve 240 transcripts, then transcripts with, at least, one stressor appraisal for five of the eight stressor appraisal responses would be selected. If more than enough eligible transcripts were available for selection at any step, they would be retained for analysis. Figure 1 summarizes the screening protocol (left) and the composition of the 240 transcripts selected for this study (right).
The 240 respondents included in this study (M = 52, SD = 12.0) were younger than those who were excluded (M = 59, SD = 11.7), t(537) = 7.63, p < .001. There was a higher proportion of women (52%) among those included as compared to those excluded (33%), χ²(1) = 19.73, p < .001. As compared to those who were excluded, there was a smaller proportion of Chinese immigrants in the respondents who were included (26% versus 18% respectively), χ²(1) = 4.21, p = .04.

3.4.3.2 Statistical methods

3.4.3.2.1 Generating and coding stressor appraisals

As noted in Section 3.2.2, each respondent answered this open-ended question—“What is the most stressful part about this situation for you?”—for the eight stressors in their assigned CRSC version. The responses to these items were used to identify the underlying reason(s) for which a given cancer-related event was experienced as stressful. These data were crucial to the central hypothesis that underlies this thesis: cancer-related events will be experienced as stressful when they threaten valued cultural values. To test this hypothesis, it was necessary to categorize the reported causes of stress as either threatening or not threatening to respondents’ underlying cultural values. The following sections describe the process used to generate and categorize these causes of stress.
3.4.3.2.1.1 Defining “stressor appraisal”

“Stressor appraisal” was operationally defined as a statement that provides a single, distinct, and unambiguous explanation for why a respondent experienced stress in a particular cancer-related situation. Stressor appraisals should be recognizable by more than one reader. Each stressor appraisal was formulated to be conceptually independent of its corresponding stressor; that is, its definition and exemplars convey the meaning of the stressor appraisal without having to refer to the stressor for clarification.

A stressor appraisal can be articulated directly (e.g., “It was stressful because…”) or it can be expressed as a psychological manifestation such as concern, worry, or fear. Experience of certain emotions can be stressful. I focused on identifying the underlying triggers of these emotions as the stressor appraisals because the hypothesis addresses the cognitive appraisal of stressors. For instance, a respondent said, “…I know they worry and that upset me too because they’re worried…” This excerpt was coded as “emotional burden on family and friends” because knowing others were worrying about him/her led to the respondent to become upset.

More than one stressor appraisal may be identified for each stressor. For example, two different stressor appraisals are evident in the following response to the cancer-related event, “I felt frustrated about my ill health.” The respondent stated, “Quite, quite stressful because I feel like I’m not contributing to, you know, society and I feel like my life has gone on hold.” We labeled the first element of this response, “I’m not contributing to…society…,” as “unable to contribute to society,” which is conceptualized as “cannot contribute to society at large” in the coding scheme developed for data analysis. The second element of the response, “…I feel like my life has gone on hold,” was labeled as “life on hold”, which is defined as “unable to plan for future or move on in life due to disease and/or treatment.”

3.4.3.2.1.2 Generating a taxonomy of stressor appraisals

Dr. Devins’ multicultural, multidisciplinary research team (including experienced psychosocial oncology clinicians and researchers, and a multicultural-nursing scholar) and I created a taxonomy of stressor appraisals (see Appendix G) to guide the coding process. Each team member received the definition of a “stressor appraisal.” Two members (the “readers”) were assigned to each transcript. They read through their assigned transcripts independently and
identified excerpts that reflected a stressor appraisal. Once completed, the readers presented their findings to the team during weekly coding meetings. When the readers agreed that an excerpt reflected a unique stressor appraisal, the team labeled the concept and developed a conceptual definition [183]. When the readers disagreed, the team discussed the issue. Once the team reached a consensus, the concept was labeled and a conceptual definition was developed. Reliance on group consensus helped to reduce bias in identifying appraisals, enhancing confidence in the objectivity of the coding [184]. In addition, the team identified and included exemplars (i.e., interview excerpts that best reflect the concept) in the taxonomy for each stressor appraisal to illustrate them and facilitate subsequent coding. Members of the research team were unaware of respondents’ scores on the revised ICS to minimize bias.

3.4.3.2.1.3 Coding stressor appraisals

Concurrent with taxonomy development, the research team identified all of the excerpts that reflected each stressor appraisal. Excerpts that reflected a given stressor appraisal that had already been identified were coded under that stressor appraisal category. When multiple excerpts within an individual’s response to a stressor reflected the same stressor appraisal, only the excerpt that best illustrated that stressor appraisal was categorized. This helped to prevent over-counting of stressor appraisals. This process continued until we coded all of the excerpts that contained a stressor appraisal in all 240 transcripts. Although this procedure is more intensive than the conventional use of “saturation” as an end point in category generation [183], our method produced an extensive list of stressor appraisal categories, which affords a comprehensive representation of stressor appraisals in the study sample. NVivo 8.0 [163] was used to organize qualitative data.

Once all of the transcripts were coded, a trained research assistant entered the total frequency of occurrence for each stressor appraisal (documented in NVivo) into a Microsoft Excel database. The data in Excel were converted into SPSS [185] for analysis.

In all, the research team identified 184 unique stressor appraisals based on 24 CRSC stressors from 240 interviews (see Appendix G). To test the hypothesis that appraisal of cancer stressors reflect threat to cultural values, I coded the stressor appraisals in terms of whether they reflect threats to the three cultural values.
3.4.3.2.1.4 Categorizing stressor appraisals based on threat to cultural values

The categorization of each stressor appraisal was based on whether the stressor appraisal reflects threats to any of the three culturally based values I extracted from the revised ICS (i.e., Commitment to Family; Camaraderie with Co-workers; and Competitiveness; see Chapters 4 and 5). A stressor appraisal was considered reflecting threats to a value when it reflected one could not (or may not) be able to behave in a fashion that was consistent with his or her values. A positive association between measures of cultural values and the frequency with which respondents reported appraisals that reflect threats to their cultural values would support the hypothesis.

The categorization of stressor appraisals was completed in two stages (see Figure 2). During the first stage (i.e., appraisal coding stage), the 184 unique stressor appraisals were sorted into two mutually exclusive groups based on whether they reflect threats to any of the three cultural values tapped by the revised ICS subscales. The resulting categories were labeled, “value-threatening appraisals” and “value-irrelevant appraisals.” This step aimed to shorten the list of appraisals for more precise categorization by removing appraisals that did not reflect threats any of the cultural values under consideration.

![Figure 2. Stressor appraisal and interview excerpt categorization procedure](image-url)
The second stage (i.e., the excerpt-coding stage) focused on coding the specific interview excerpts associated with the stressor appraisals that were considered to reflect threats to respondents’ values. Recall that all interview excerpts that reflected the same stressor appraisal were assigned the same category (see Section 3.4.3.2.1.3). During this excerpt-coding stage, the interview excerpts associated with value-threatening appraisals in Stage 1 were coded according to whether they reflect threats to one or more of the cultural values. This meant that an excerpt could be assigned to one or more categories: (a) excerpts that reflect threats to camaraderie with co-workers;” (b) excerpts that reflect threats to commitment to family; and/or (c) excerpts that reflect threats to competitiveness. In some cases, specific excerpts may not have appeared to reflect threats any of the cultural values under consideration. These were categorized as “value-irrelevant excerpts.”

Krippendorff’s alpha [186,187] was used to estimate inter-rater reliability. This statistic was selected in favor of the more common indices e.g., coefficient kappa [188], because its estimate is based on the subset of categories that coders actually used, rather than all available categories in the codebook. Thus, this statistic is based more on empirically observed consistency as compared to reliability based on a theoretically anticipated distribution of the data [186]. This is particularly important for the excerpt-coding stage because some of the available categories may not have any excerpts assigned to them. For example, during excerpt coding, the coders were allowed to assign an excerpt to more than two categories. If the coders did not use one of the categories, such as stressor appraisals that reflect threats to competitiveness, reliability estimation would exclude that category from the calculation. Krippendorff’s alpha $\geq .80$ is considered to indicate acceptable reliability [189]. Highly tentative conclusions may be drawn when Krippendorff’s alpha ranges between .67 and .80.

I trained two independent coders to perform the coding process. Coders were blinded to the study hypothesis to maintain objectivity. I developed a codebook for each stage (see Appendices H & I). I worked with the two coders to revise and improve the codebook during training. During training for stressor appraisal coding (i.e., Stage 1), coders practiced using the codebook to assign stressor appraisals to the two categories (i.e., “value-threatening appraisals” and “value-irrelevant appraisals”). During each training session, coders worked with a randomly selected subset of appraisals that comprised 10% of the entire pool of stressor appraisals. Issues that arose during this phase were discussed and clarified. Inter-rater reliability was assessed after each
training session to determine when the coding protocol could be applied consistently. The inter-rater reliability of the final pilot-test coding of stressor appraisal coding was .82, which is within the acceptable range [189]. Thus, the coders proceeded to assign the remaining stressor appraisals to categories.

The top portion of Figure 3 summarizes the results of stressor appraisal coding (i.e., Stage 1). Both coders identified 28 (15%) value-threatening appraisals (e.g., “Communicating diagnosis with loved ones”) and 118 (64%) value-irrelevant appraisals (e.g., “Difficulty accessing medical expertise”). However, the coders did not agree on the coding of 38 (21%) appraisals (i.e., “discrepant-coding appraisals”). I randomly selected 50% of the final categorization to estimate inter-rater reliability [190]. Krippendorff’s alpha was .43. This lower-than-expected result may be attributable to the abstract nature of the task. Much interpretation was required to determine whether stressor appraisals reflected threats to cultural values. To improve the specificity of the data available to coders, they were asked to code individual interview excerpts in the next coding stage (i.e., excerpt coding stage). The justification was that it would be easier to apply codes accurately when the coders consider more specific instances of the stressor appraisals.

The second, more precise coding stage involved assigning interview excerpts into categories by determining whether they reflect threats to one or more of the cultural values under consideration. The same coders were trained using a training procedure similar to that employed for stressor appraisal coding (i.e., Stage 1). After several rounds of pilot-testing and discussions concerning discrepant results, the final pilot-test reliability assessment, using Krippendorff’s alpha, was .76, which approaches the recommended level of .80 for acceptable reliability [189]. Thus, coders proceeded to assign categories the remaining interview excerpts.

All of the interview excerpts \((n = 1225)\) that were coded under the 23 value-threatening appraisals and the 33 discrepant-coded appraisals were compiled for coders’ consideration (see Figure 3). Both coders identified 105 (8%) excerpts reflecting threats to commitment to family (e.g., “I don’t, wouldn’t want [my children] to go through the grief of losing their mother.”); 36 (3%) excerpts reflecting threats to both commitment to family and camaraderie with co-workers
(e.g., “…because I know they worry and that upset me too because they’re worried” ³); and 979 (80%) excerpts that did not reflect threats to any of the cultural values under consideration (e.g., “…[being sick] was hard ‘cause normally I’ve been healthy and just being so sick was stressful.”). The coders disagreed on the coding of 105 (8%) excerpts (i.e., discrepant-coded excerpts). Inter-rater reliability for this stage, as measured by Krippendorff’s alpha, was .50. Two reasons may have contributed to the lower than desired inter-rater reliability (i.e., Krippendorff’s alpha ≥ .67; [189]). First, the coders received only a list of interview excerpts for consideration. It may be challenging for coders to comprehend the meanings of an excerpt without reference to the entire response that discusses the causes of stress for a particular cancer stressor. Second, the coders’ task was to determine whether each excerpt reflected a threat to cultural values. This required considerable subjective interpretation, which may have contributed to categorization inconsistencies, similar to Stage 1 coding. As a result, inter-rater reliability was lower than generally acceptable. In subsequent analyses, therefore, I included only the 105 excerpts reflecting threats to commitment to family that were coded consistently by both coders to avoid

³ “They” in this excerpt can be referred to a family member or a co-worker and therefore, it was coded under reflecting threats to both Commitment to Family and Camaraderie with Co-workers.

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**Figure 3.** Final value-threatening appraisal and excerpt categorization results
errors attributable to unreliability.

3.4.3.2.2 Testing the hypothesis

I hypothesized that people would identify stressor appraisals that reflect threats to their cultural values. Since the independent coders did not identify any excerpt reflecting threat to camaraderie or competitiveness, I could only test this hypothesis in relation to commitment to family. Thus, I regressed the Commitment to Family score derived from the revised ICS, on the number of appraisals reflecting threats to commitment to family the respondents reported. I used hierarchical Poisson regression analysis, rather than an analysis based on the ordinary least squares criterion, because the number of appraisals reflecting threats to commitment to family was small and the distribution was positively skewed [191]. Correlational analyses were used to identify covariates. In the first step of the hierarchical Poisson regression analysis, empirically identified covariates were entered into the regression equation; in the second step, the Culture Group was entered; in the third step, Commitment to Family score was entered; and in the final step, the Culture Group x Commitment to Family interaction term was entered to test the moderating effect of culture group on the relation between commitment to family and the number of appraisals reflecting threats to that value.

The Poisson regression model tests the natural log-based changes in the dependent variable as an explanatory variable increases by one unit [191]. It assumes that the conditional variance of the outcome is equal to its mean. When the variance is greater than the mean, the model is considered “overdispersed” [191,192]. Overdispersion can result in (a) underestimation of standard errors (SEs) and confidence limits and (b) overestimation of the statistical significance of parametric estimates (i.e., \( p \)-values would be lower than they would otherwise be; [191]). To ensure the assumption was satisfied in this analysis, two alternative models were tested: (a) an overdispersed Poisson regression model and (b) a negative binominal model [191]. The overdispersed Poisson regression model includes a scaling factor—the ratio between the deviance (i.e., an indicator of how “poor” the model fit is as compared to the perfect model) and its corresponding degrees of freedom (\( df \)). When the scaling factor is greater than 1, it indicates that overdispersion is present. The negative binominal model assumes that unexplained variability exists among individuals, which results in larger than normal variances in a Poisson distribution of the outcome. The negative binominal model adjusts for overdispersion by including a
parameter ($\alpha$) in its variance estimate. When $\alpha$ is greater than zero, it indicates that the data are overdispersed.

I conducted two sets of comparisons to determine whether the original Poisson, overdispersed Poisson, or negative binomial model provided the best fit—i.e., the extent to which the model best estimates the relations between the variables of interest. The overdispersed Poisson and the negative binomial models are not nested models (i.e., the scaling factor and the parameter $\alpha$ differed for each hierarchical step in the overdispersed Poisson and negative binomial models, respectively). Hence, they cannot be compared directly using the common method of comparing their deviance, which indicates how “poor” the fit is compared to a perfectly fitting model [191,192]. Thus, we compared the Akaike Information Criterion (AIC) and the Bayesian Information Criterion (BIC) between the three models at the same step in the analysis [193]. This approach allowed us to compare nested and non-nested models directly. Lower values indicate better fit.

Once the appropriate model was selected, I examined changes in deviance among the hierarchical models [191]. Reduced deviance between current and preceding steps in a hierarchical Poisson regression reflects the extent to which the model’s fit has improved after adding the predictor(s) at each step. Chi-square test was used to determine the statistical significance of the reduction in deviance by adding predictors at each step. To estimate the effect size of each reduction in deviance, we converted the change in deviance to phi coefficient ($r_\phi$) [194]. A $r_\phi$ of .10, .30, and .50 reflect small, medium, and large effect size, respectively [195,196].

Because the Culture Group x Commitment to Family interaction effect was statistically significant (see Chapter 6), it was plotted to facilitate interpretation of the result. Because most standard statistics software such as SPSS do not have a function to plot a Poisson regression, I used a Microsoft Excel template developed by Dr. Jeremy Dawson [197] to graph this interaction effect. It produces a line graph with Commitment to Family as a bi-level variable (i.e., high or low Commitment to Family) on the x-axis and the natural log of the mean number of appraisals reflecting threats to commitment to family on the Y-axis. The logarithm mean count of appraisals reflecting threats to commitment to family for those with low Commitment to Family
and those with high Commitment to Family were plotted and joined by a curvilinear line. Data for each culture group were graphed on a separate line.

A statistically significant 2-way interaction term indicates the slope of the two lines is different from one another. I also tested the slope of each line to determine whether the relation between Commitment to Family and the appraisals that reflect threats to that value was significantly different in the two culture groups. Using the method described by Dawson [198], I tested the significance of each slope by referring the ratio between the slope to its standard error to the $t$ distribution (with a degree of freedom of $n - k - 1$, where $k$ is the number of predictors in the model).

3.4.3.2.3 Testing competing hypotheses

We cannot manipulate specific respondent characteristics to rule out competing explanations to our findings in naturalistic research. An alternative approach is to conduct statistical analyses to test plausible competing hypotheses. If none of the competing factors significantly moderate the relationship of interest, we can be more confident about our interpretations. For this study, I tested the competing hypotheses that each of the following respondent characteristic moderates the relation between commitment to family and the appraisal of stressors as threatening to this cultural value: sex (a proxy measure for gender [199]), age (a proxy measure for life stage [200]), and proportion of life lived in Canada (a proxy for acculturation [201]). Evidence suggests that the meaning of family and one’s role within it vary depending on one’s gender, life stage, and acculturation. Women tend to be more sensitive to negative events that affect their family than men [202,203]. The meaning of family and familial responsibilities changes over one’s lifespan as a function of changing familial roles (e.g., dependent, parent, and grandparent) [200]. For example, parents’ of young children tend to focus on their parental responsibilities [204], whereas the elders try not to become a burden to their adult children [205]. Those who are more acculturated tend to adopt some of the cultural values of their host countries (e.g., familial obligations as voluntary commitments [78,206]) to a greater extent than those who are less acculturated [207].

I conducted separate sets of hierarchical Poisson regressions to rule out plausible competing explanations (e.g., gender, life stage, and acculturation) of the observed relation between the endorsement of commitment to family and the reporting of stressor appraisals that reflect threats
to one’s sense of commitment to family. I used the same hierarchical Poisson protocol as described in Section 3.4.3.2.2.1 to test competing hypotheses. For example, to test the moderating effect of sex, I enter empirically derived covariates in the first step; Culture Group in the second step; Sex in the third step; 2-way interaction terms (i.e., Culture Group x Commitment to Family and Sex x Commitment to Family) in the fourth step; and the 3-way (i.e., Sex x Culture Group x Commitment to Family) interaction term in the final step. Similar hierarchical Poisson regressions were conducted, substituting Sex for Age and Proportion of Life Lived in Canada separately, to test their moderating effects. Reduction in deviance between each hierarchical step was calculated and its effect size ($r_\phi$) was estimated [194].
Chapter 4
Measuring Individualism and Collectivism in Adult Head and Neck Cancer Survivors

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Abstract

Society’s increasing diversity calls for further examination of culture’s role in illness experience. Individualism-collectivism is among the most commonly studied cultural factors, yet it has rarely been examined as a determinant of the psychosocial impact of disease. We examined the measurement invariance of English and Chinese versions of the widely used Individualism-Collectivism Scale (ICS) in adult head and neck cancer (HNC) survivors, including Western-born Caucasians (n = 403) and Chinese immigrants (n = 119). Confirmatory factor analysis (CFA) disconfirmed the original 4-factor model. We concluded that the ICS does not measure individualism-collectivism as purported. Subsequent exploratory factor analysis identified a new 3-factor structure: (a) Camaraderie with Co-workers; (b) Commitment to Family; and (c) Competitiveness. We conducted CFA on the new model using HNC data from which it was derived. The model achieved weak invariance. We propose this as a promising, alternative measurement-model to tap cultural values in adult HNC survivors.

Keywords: vertical-horizontal individualism-collectivism, cultural values, confirmatory factor analysis, exploratory factor analysis, measurement invariance, head and neck cancer, cross-cultural research
Introduction

As the diversity of society grows, it becomes increasingly important to understand cultural determinants of illness experience. Investigators often rely on ethnicity or country of origin as proxies to represent this important factor, but specific culturally salient values and beliefs can offer more direct explanations for the effects of culture [81]. “Cultural syndromes” are multifaceted vectors of values, attitudes, and beliefs that center on a theme [79]. Because they capture fundamental differences about how people make sense of the world, cultural syndromes can help us to understand diverse responses to disease.

Vertical-horizontal individualism and collectivism are among the most commonly studied cultural syndromes. These cultural syndromes subsume a large number of cross-cultural differences under a smaller number of dimensions that manifest in perception, motivation, and behavior [78]. Vertical-individualism (VI) emphasizes improving one’s status as an individual and distinguishing oneself from others; horizontal-individualism (HI) places value on status equality, self-reliance, and the expression of uniqueness; vertical-collectivism (VC) emphasizes respect for authority and maintenance of social cohesion, even when this requires self-sacrifice; and horizontal-collectivism (HC) stresses sociability and interdependence with others in an egalitarian social environment [79,93]. Although these four cultural syndromes are conceptually distinct, people do not adhere to a single one; rather, people maintain a uniquely weighted combination of cultural syndromes. It is variations in the extent to which people adhere to these cultural syndromes that lead to cross-cultural differences in motivations, emotions, and behaviors [79,97,98].

Vertical-horizontal individualism and collectivism correspond to important aspects of life, such as self-expression, relationships, and work [79]. When disease threatens culturally valued life domains, people experience worry and concern [152,153]. For example, Uskul and Hynie [12] found that those who endorse predominantly individualist cultural syndrome tend to construe the effects of disease in more personal ways (e.g., being unable to do things independently), whereas people who maintain primarily collectivist cultural syndrome tend to appraise disease in more interpersonal terms (e.g., being unable to fulfill social responsibilities). Considering the affected person’s dominant cultural values can increase our understanding of the specific reasons why people experience disease as stressful. This is especially relevant for stigmatizing, life-
threatening conditions that are prevalent among diverse culture groups, such as head and neck cancer (HNC) [14].

Before such speculations can be tested, however, it is crucial that psychometrically sound measures of cultural syndromes be available. The 16-item Individualism-Collectivism Scale (ICS) [91] is a widely used psychological measure of vertical-horizontal individualism and collectivism. The ICS comprises four subscales (i.e., VI, HI, VC, and HC), each includes four items. Respondents indicate the extent to which they agree or disagree with the 16 statements using a rating scale (1=“disagree very much;” 9= “agree very much”). The ICS has been used in research to examine a wide range of issues in cultural psychology, including intergroup negotiations [130] and work relationships [131]. As a purported measure of cultural differences, it has been applied to compare people from different cultures.

However, measurement invariance of the ICS’s underlying factor structure across groups has been an issue. An instrument is said to demonstrate measurement invariance when identical factor solutions provide a good “fit” to response data across respondent groups that differ systematically in one or another characteristic (e.g., culture) [208]. It is established after testing an instrument’s underlying factor structure in different groups and establishing that the items consistently reflect the same latent constructs across the groups [114,115]. Measurement invariance is crucial to effective measurement in cross-cultural research because it substantiates the validity of inferences and interpretations of study findings [208]. Confirmation of invariance helps to rule out the competing hypothesis that measurement-related inconsistencies across groups, rather than the hypothesis under consideration, explains observed results.

Evidence supporting the measurement invariance of the 4-factor ICS measurement model has been inconsistent. Some studies found support for invariance across English and non-English versions [74,108], but others were unable to cross-validate this model [133-135]. Moreover, research to date has relied primarily on college-student respondents. Generalizability to the adult population, either in good health or living with chronic illness, is uncertain. This is unfortunate because the ICS has obvious relevance given the widespread belief that culture exerts powerful effects on the experience and psychosocial impact of chronic, disabling, and life-threatening conditions [5]. Validation of the ICS’s hypothesized measurement model is clearly the next
logical step. This must be established before proceeding to investigate these important cultural factors as they relate to the psychosocial impact of disease.

The present paper addresses the cultural equivalence of the English version of the ICS and a Chinese translation our research group developed. The data were gathered in the context of a larger study designed to investigate vertical-horizontal individualism and collectivism, age, and sex as moderators of the quality-of-life impact of illness intrusiveness (i.e., illness-induced disruptions to valued activities and interests) [44] in HNC. The respondent sample included adult HNC survivors who are Western-born-Caucasians and Asian-born Chinese-immigrants. We targeted these populations to maximize the range of vertical-horizontal individualism and collectivism represented in the data. Caucasians are often included in research as proxy for members of individualist cultures and Chinese for collectivist cultures (e.g., [86,100,102,103]). We used confirmatory factor analysis (CFA) to test the measurement invariance of the original 4-factor ICS measurement model between these two groups. However, because the model did not provide a good fit to the data from either group, we then conducted exploratory factor analysis (EFA) to derive a new measurement model and then another series of CFAs to evaluate the new measurement model.

**Methods**

**Participants**

We sampled HNC outpatients attending a large, university-affiliated cancer center in Toronto, Canada. Eligibility criteria included: age 18 years or older; self-reported Western-born Caucasian or Chinese immigrant; diagnosed malignancy of the head and neck; undergoing routine medical follow-up following treatment with curative intent; and fluent in English, Cantonese, or Mandarin. All respondents provided informed consent, and the study received institutional ethics approval.

We recruited 539 adult HNC survivors. Analyses were conducted using data only from respondents who provided complete ICS data \( n = 522; 97\% \). Respondents who provided complete data reported shorter durations since diagnosis \( (M = 1.44 \text{ years}; SD = 1.30) \) than those who had missing data \( (M = 3.10 \text{ years}; SD = 3.94) \), \( t(8) = 3.17, p = .014 \).
Among those who provided complete data, 403 (77%) were Western-born Caucasians and 119 (23%) Chinese immigrants (Table 1 reports participant characteristics). Most Caucasians ($n = 328; 81\%$) were born in Canada or the US (hereafter known as “North American-born”). The remaining Caucasians (hereafter known as “foreign-born”) were born in Europe ($n = 69; 17\%$), Central or South America ($n = 4; 1\%$), or South Africa ($n = 2; 0.5\%$). Of these, 27 (88\%) arrived in Canada at age 12 or younger. North American-born and foreign-born Caucasians did not differ systematically in demographic or clinical characteristics, except that the former were younger ($M = 56.11; SD = 12.99$) than the latter ($M = 59.88; SD = 10.44$), $t(132) = 2.69, p = .008$. Because the sample included comparatively few foreign-born Caucasians, we pooled the Caucasian data despite the age difference; their exclusion did not affect the results in any way.

Among Chinese immigrants, 58 (49\%) were born in Hong Kong and 47 (39\%) in mainland China; the remainder ($n = 14; 12\%$) originated in Southeast-Asian countries, such as Vietnam or Singapore. Most ($n = 110; 92\%$) came to Canada at age 18 or older. Because country of birth was not systematically associated with any demographic or clinical characteristics, we pooled the Chinese data for analysis.

**Measure**

**Individualism-Collectivism Scale (ICS)**

When we initiated the research, we obtained the most current version of the ICS from the author (H.C. Triandis, personal communication, 2000); we have noted, however, that this version has not been published to date. We compared item content between the version we obtained and its published predecessors to ensure comparability. Published ICS versions include: (a) a 32-item version [82]; (b) a 29-item version [98]; and (c) a 16-item version [91]. The items in our version were most similar to those of the 16-item ICS, with a few minor differences in wording between the two versions (e.g., “It is important that I do my job better than others,” versus “It is important that I perform my job better than others”). Hence, we employed the same 16 items in all analyses reported in this paper.

The Chinese version was developed for an earlier study (also led by the senior author) using a standard back-translation protocol [111]. Bilingual research-team members involved in the study (including a multicultural-nursing scholar, a professional translator, and the first author)
reviewed the English and Chinese versions independently and confirmed that the items were comparable between them. All Western-born Caucasians completed the English version, whereas all Chinese immigrants completed the Chinese version.

The English VI and HC subscales (Cronbach’s $\alpha = .70$ and .76, respectively) showed adequate internal consistency, but the HI and VC subscales did not (Cronbach’s $\alpha = .62$ and .65, respectively). The Chinese HI, VC, and HC subscales showed satisfactory reliability (Cronbach’s $\alpha = .73$, .83, and .78 respectively), but the VI subscale did not (Cronbach’s $\alpha = .53$). These reliability estimates are comparable to other published ones. Torelli and Shavitt [74] reported Cronbach’s $\alpha$s range from .62 to .80 for the HC subscale and .66 to .83 for the HI subscale. Sivada et al. [133] reported Cronbach’s $\alpha$s between .41 and .67 for the HC subscale and between .21 and .72 for the VI subscale.

**Statistical Methods**

**Measurement Invariance of the Original ICS Measurement Model**

We conducted CFAs, using EQS for Windows (version 6.1), to evaluate measurement invariance of the original 4-factor model. An instrument is considered to achieve measurement invariance when items represent their respective latent factors in the same ways across groups [164]. This must be confirmed prior to comparing group means to rule out the alternative interpretation that observed differences arose due to measurement inconsistencies.

The first step is to establish fit of the basic measurement model within each group [164]. Subsequent testing of measurement invariance across groups is not justified if the model does not demonstrate good fit in each group. We had sufficient numbers of Western-born Caucasian and Chinese immigrant respondents (i.e., a ratio > 5:1 of participants to items) [113] to test the hypothesized measurement model reliably in each culture group. We tested three models: (a) the original 4-factor model (i.e., VI, HI, VC, and HC) [91]; (b) an alternative 3-factor model (i.e., VI, HI, and COL) [82]; and (c) an alternative 2-factor model (i.e., IND and COL) [80]. Because CFA results can be compromised when data are distributed non-normally, we examined robust fit indices, which adjust for this problem [165]. We used the following goodness-of-fit criteria to evaluate model fit [113,165]: Satorra-Bentler (SB) scaled $\chi^2/df$ ratio, non-normed fit index (NNFI), comparative fit index (CFI), adjusted goodness-of-fit index (AGFI), standardized root
mean squared residual (SRMR) and root mean-square error of approximation (RMSEA). We considered model fit to be “excellent” when fit indices achieved the following criteria [113,165]: SB $\chi^2/df$ ratio < 2.0; NNFI, CFA, and AGFI > .90; and SRMR and RMSEA $\leq$ .08. Others have suggested that a $\chi^2/df$ ratio < 3 indicates acceptable fit [166,167]. We used the Lagrange Multiplier (LM) test to identify post-hoc modifications to improve model fit [164].

**Exploratory Factor Analysis to Identify an Alternative Model**

As will be reported in detail below, CFA results showed adequate fit of the original ICS measurement model in data from Western-born Caucasian data but not in data Chinese immigrant HNC survivors. The alternative models fit neither group’s data. We therefore identified alternative latent-factor structures by conducting separate EFAs with varimax rotation [168,170] for each respondent group, using SPSS (version 18.0). We employed the principal-factor extraction method because some item scores were skewed [168,171]. We relied on scree plots to inform factor retention rather than the “eigenvalue > 1” rule, because the latter tends to retain factors that can prove insufficiently reliable or reproducible [170,209]. We retained items and assigned them to a given factor when (a) they loaded uniquely on a single factor and (b) their loadings exceeded .32 [113,170].

**Measurement Invariance of the Newly Proposed Model**

We then conducted a second series of CFAs to verify the measurement invariance of the newly extracted model. Although it is more common to cross-validate model fit using independent samples, we did not have data from another HNC-survivor group. Some authorities maintain that it is reasonable to employ CFA to initially test goodness of fit of an EFA-extracted model using the same data [173]; if the CFA results do not corroborate the EFA findings, the model is unlikely to show good fit in independent samples. Hence, as a first step in validating the new EFA-derived model, we tested its measurement invariance using the same HNC Western-born Caucasian and Chinese immigrant data from which it was derived.

We began by applying the same CFA procedure and goodness-of-fit criteria as described earlier, to determine whether the new measurement model fit well to data from the two groups separately. Because we established model fit for each group, we proceeded to conduct a multi-sample CFA (MSCFA). This entails a rigorous, multi-step approach testing model fit
simultaneously in Western-born Caucasians and Chinese immigrants. We employed means and covariance structure analysis (MACS) [164] to evaluate measurement invariance. This hierarchical approach tests increasingly rigorous levels of invariance of different model parameters [115,164]: (a) configural invariance (i.e., the basic factor structure is equivalent across groups); (b) weak invariance (i.e., configural invariance is met and the factor loadings are equivalent); (c) strong invariance (i.e., weak invariance is met and the item intercepts are equivalent); and (d) strict invariance (i.e., strong invariance is met and the items error variances are equivalent). To test levels of invariance, we sequentially added sets of equality constraints (i.e., to define the corresponding set of parameters as equivalent across groups; one set for each level of invariance) to the model after establishing configural invariance [165]. Invariance at each step is supported when (a) a $\chi^2$-difference test shows non-significant change (i.e., $p > .05$) in $\chi^2$ between the current model with the equality constraints and the preceding one that did not include them [164], and (b) the model satisfies goodness-to-fit criteria [113,165]. The model must demonstrate cross-group invariance at one step before it is valid to test the next, more rigorous level of invariance (i.e., the models hierarchically nested). At each step, we performed LM tests to identify post-hoc modifications that would improve goodness of fit if necessary [164].

The established level of invariance indicates the extent to which valid interpretations and syntheses of test scores can be made across respondent groups. When an instrument is characterized by weak invariance, it is valid to compare hypothesized associations between the mean latent-scores and other variables across groups [114,176]. When an instrument demonstrates strong or strict invariance, it is possible to conduct valid comparisons of mean latent-scores across groups [164,174,175].

**Results**

**Measurement Invariance of the Original ICS Measurement Models**

Table 2 summarizes the CFA results. The original 4-factor model showed adequate fit in data from Western-born Caucasians but not in data from Chinese HNC immigrants. None of the alternative models tested fit the data from either group. Therefore, there was no justification to test between-group measurement invariance. As a result, we conducted EFAs to identify an alternative latent-factor structure.


Exploratory Factor Analysis

EFA results differed between the Western-born Caucasians and Chinese immigrants. Scree plots indicated a 5-factor solution for the Western-born Caucasian data, but a 3-factor solution for the Chinese immigrant data (see Table 3). The 5-factor solution explained 45.0% of the variance in Western-born Caucasian responses. Many of the items loaded on the original four factors: two original HC items and one VC item loaded uniquely on Factor 1; all four VI items loaded on Factor 2; three VC items loaded on Factor 3; two HI items loaded on Factor 4; and another HI item loaded on Factor 5. In the Chinese-immigrant data, the 3-factor solution explained 48.1% of the variance. Eleven of the 16 items (i.e. four VC items, four HI items, two HC items, and one VI item) were loaded on Factor 1; five items (i.e., four HC items and one VC item) on Factor 2; and four items (i.e., three VI items and one HI item) on Factor 3 (see Table 3).

Because the two solutions differed substantially, it was not valid to pool the data to derive a common factor structure. Rather than abandoning the goal of developing a culturally equivalent measurement model, we adopted a novel approach to extract new subscales: for each factor, we selected items that loaded onto a single factor in both groups because these items shared substantial variance, suggesting that they tap a common underlying construct in each group [113,170]. This strategy offers an alternative way to identify items that measure the same concept in both groups.

We extracted three factors for this new model because this was the maximum number of factors observed for the two groups (see Table 3). We derived a common factor with the items, “If a coworker gets a prize, I would feel proud” and “The well-being of my coworkers is important to me,” because they loaded onto the same factors in each culture group. We labeled this factor “Camaraderie with Co-workers” because the items reflect concern for the well-being of one’s colleagues. The second factor consists of three items that loaded onto a single factor within each group, “It is important that I perform my job better than others,” “Winning is everything,” and “When another person does better than I do, I get tense and feel challenged.” We labeled Factor 2 “Competitiveness” because the items tap the value of outperforming others in competitive contexts. For the third factor, the three items, “Family members should stick together, no matter what sacrifices are required,” parents and children must stay together as much as possible,” and “It is my duty to take care of my family, even when I have to sacrifice what I want,” loaded onto
a single factor in each culture group. We labeled Factor 3 “Commitment to Family” because the
items reflect dedication to family well-being and a willingness to self-sacrifice to ensure family
needs are met. Cronbach’s $\alpha$ for the English and Chinese versions, respectively, were as
follows: Camaraderie with Co-workers = .72 and .69; Commitment to Family = .65 and .66; and
Competitiveness = .65 and .56.

**Measurement Invariance of the Proposed New Model**

To test the invariance of the new 3-factor model, we first conducted separate CFAs of the new
model on the Western-born Caucasian and Chinese-immigrant data to confirm basic model fit.
The new 3-factor model demonstrated excellent fit to the Western-born Caucasian data.
However, two additional parameters, as recommended by LM test, were required to meet
goodness-of-fit criteria for the Chinese immigrant data (details can be obtained from the first
author). We included these additional parameters in the model for the Chinese immigrant sample
in the subsequent MSCFA. Because the 3-factor model fit sufficiently well for each group
considered independently, we proceeded to test it using MSCFA.

Table 4 summarizes the MSCFA results. The new 3-factor model achieved configural invariance.
When we tested the equality constraints for weak invariance, the $\chi^2$-difference test showed a
statistically significant change in $\chi^2$, indicating that factor loadings were not equivalent across
groups. The LM test suggested releasing the equality constraint for the factor loadings for the
Commitment to Family item, “It is my duty to take care of my family, even when I have to
sacrifice what I want.” This resulted in good model fit, a non-significant $\chi^2$-difference test, and
partial weak invariance. However, this post-hoc modification suggests that the item, “It is my
duty to take care of my family, even when I have to sacrifice what I want,” contributes to the
meaning of Commitment to Family construct differently for the two groups. Since our goal was
to derive a common factor structure that fits both Caucasian and Chinese HNC data, we decided
to remove this item from the Commitment to Family subscale and retest a new 3-factor structure
consisting of seven items, with two items now representing the Commitment to Family factor.

Table 5 summarizes the MSCFA results on the 7-item, 3-factor model. This model showed
excellent fit at the levels of configural and weak invariance, as demonstrated by the fit indices
and the non-significant $\chi^2$-difference. Although the model met most of the criteria for excellent
model fit at the strong invariance level, the $\chi^2$-difference test showed a significant change in $\chi^2$. 
Since none of the LM test recommendations for improving model fit seemed theoretically justifiable, we concluded that the new 7-item, 3-factor model achieved weak invariance. Figure 1 reports the final standardized parameter estimates for factor loadings, error variances, and intercorrelations among the three latent factors at the level of weak invariance. All factor loadings were significant at $p < .05$.

**Discussion**

In this study, we tested the measurement invariance of English and Chinese versions of the 16-item ICS [91]. Based on observed CFA results, the hypothesized 4-factor model of the ICS showed adequate fit in data from Western-born Caucasians but not in data from Chinese immigrants with HNC. Alternative 2- and 3-factor models also did not fit well with data from either group. These findings provide further converging evidence that the original measurement model for the 16-item ICS does not tap the concepts as hypothesized, at least in the HNC population.

It is important to emphasize that our findings do not disconfirm the vertical-horizontal individualism and collectivism conceptual framework proposed by Triandis [79]. Although the original measurement model may not apply to adult HNC survivors, the items may still capture constructs that are relevant and meaningful across culture groups. Thus, we conducted EFAs to identify an alternative measurement model tapped by the items.

We selected eight items that loaded on three factors to form a common factor structure that might apply across the groups: Camaraderie with Co-workers, Commitment to Family, and Competitiveness. The extracted factors no longer measure vertical-horizontal individualism and collectivism; rather, they appear to tap constructs that conceptually reflect more specific aspects of vertical-horizontal individualism and collectivism. Specifically, camaraderie with co-workers emphasizes caring for one’s peers, which relates to the HC notion of interdependence in an egalitarian social environment [106]. Commitment to family stresses obligations to one’s family’s well-being and includes making self-sacrifices when necessary. This is central to the VC values of respecting authority and maintaining social cohesion at all costs [106]. Competitiveness emphasizes striving for superiority, a VI facet that involves distinguishing oneself from others and improving personal status [106]. Triandis and Gelfand [91] observed similar associations among the overarching concepts of HC, VC, and VI, and these three factors
that are comparable to our new factors: HC with interdependence; VC with maintaining family integrity; and VI with competitiveness. Upon establishing the new factors’ construct validity, the use of these more specific cultural constructs has the potential to increase conceptual clarity and to achieve more interpretable and reliable measurements [78].

The new measurement model initially demonstrated partial weak invariance in the HNC data from which it was derived. The post-hoc modification to the model (i.e., releasing the factor loading constrain for the item, “It is my duty to take care of my family, even if I have to sacrifice what I want”) may be attributable to varying conceptualizations of familial responsibility in Western-born Caucasians and Chinese immigrants. The Chinese immigrants showed a higher factor loading (.70) than the Western-born Caucasians (.57) for that item. This means that in Chinese immigrants, the concepts of duty and self-sacrifice in the service of familial responsibilities appear to exert more influence in formulating the concept of Commitment to Family as compared to Western-born Caucasians. Although people from Western cultures (e.g., as represented by Americans) and from Chinese cultures value family relationships, the latter emphasizes self-sacrifice as obligatory in the service of family needs (e.g., [210,211]). People from Western cultures, on the other hand, tend to consider the fulfillment of family obligations as something over which one can exercise choice (i.e., discretionary) [78]. Because the contribution of this item to the meaning of Commitment to Family varied greatly between the Caucasian and Chinese data, we opted to remove it to achieve a more stringent level of invariance.

The new 7-item model’s fit improved to the level of weak invariance. As a result, scores for the new model can be employed in correlational analyses [114,176]. We do not imply that the new subscales are comprehensive measures of camaraderie with co-workers, commitment to family, or competitiveness; rather, they offer researchers a consistent way to assess the relationship of these constructs with other variables of interest, at least between Western-born Caucasians and Asian-born Chinese immigrants with HNC. Commitment to family may help to further understanding about, for example, why some people with cancer are willing to respect family preferences for non-disclosure of the diagnosis, whereas others may have difficulty doing so [212] or the ways in which family influences coping with cancer [213]. Another important issue in cancer involves return to work following cancer treatment [214]. This work could certainly be informed by incorporating the notions of competitiveness and camaraderie with co-workers into
theoretical analyses and testing them empirically. We did not observe strong invariance despite post-hoc model modifications. This indicates that the groups do not share common intercepts. When two groups with different intercepts endorse an item to the same extent, the group with a higher intercept will, in actuality, have a lower factor score [215]. Thus, group differences in subscale means cannot be interpreted directly.

Some limitations must be recognized in interpreting the present results. Some of the subscales did not satisfy minimum reliability criteria for research purposes (i.e., Cronbach’s $\alpha \geq .70$) [118]. This may be due to the small numbers of items that comprise the new subscales [216]. Other IND-COL instruments have the same problem due to the challenges inherent in reliance on a small number of items to measure a complex, global construct [78,82]. Generating additional items for the new subscales may help to improve internal consistency [116]. Another issue is that we tested the original 4-factor ICS measurement model using data from adult HNC survivors, whereas the original model was derived from college-student samples. The fact that the model did not provide a good fit to these data may therefore be attributable to one or more unique characteristics of our HNC samples. Successful cross-validation of the new model in independent HNC samples or other chronic-disease samples would confirm its generalizability. A third issue is that the new 3-factor measurement model was a “hybrid” (i.e., it was derived in part through EFA and in part through selection of items based on the fact that they loaded on the same factor in both groups). Although this method was unconventional, it presents a promising analytic model by which to compare cultural syndromes across Western-born Caucasian and Chinese immigrant HNC survivors. The MSCFA results supported the merits of this approach by demonstrating that the new measurement model achieved weak invariance in two culture groups. Cross-validation of the new model in HNC and other populations is needed to verify the fit and generalizability of the model.

**Conclusions**

Cultural syndromes can enhance understanding of culturally based differences in illness experience. Before proceeding to test hypotheses about the relations between these cultural syndromes and illness experience, however, it is crucial to establish that measures of cultural syndromes show invariant factor structures across groups to substantiate the validity of observed cross-group differences. Measurement refinement remains to be undertaken, but the newly
derived model reported in this research offers a valuable alternative for researchers who wish to understand the psychosocial influence of cultural factors more effectively, both in healthy and in clinical adult populations.
Figure Caption

Figure 1. The newly derived 3-factor model at the level of weak invariance. The final standardized parameter estimates for the factor loadings, error variances, and inter-correlations for the 3-factor structure at the level of weak invariance for HNC Western-born Caucasians and Chinese immigrants. The factor structure is illustrated by the three factors and solid-arrow regression lines pointing to their respective items; these arrows reflect the regression of the items on their respective factors (i.e., factor loadings). The latent factor intercepts are represented by the open-arrow dashed regression lines pointing from the Constant to each factor. Post-hoc adjustments for the HNC Chinese immigrants are represented by open-arrow dash-dotted regression lines, pointing from a factor to an item. The three factors’ disturbances are permitted to correlate among each other. Regression lines associated with item intercepts are excluded. Each parameter value is reported in the following order: HNC Western-born Caucasians and Chinese immigrants.
Table 1. Participant characteristics for HNC Western-born Caucasians \((n = 403)\) and Chinese immigrants \((n = 119)\)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Western-born Caucasians</th>
<th>Chinese immigrants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n (%))</td>
<td>(M (SD))</td>
</tr>
<tr>
<td><strong>Demographics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age *</td>
<td>56.81 (12.63)</td>
<td>52.14 (11.34)</td>
</tr>
<tr>
<td>Men</td>
<td>240 (60)</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>290 (72)</td>
<td></td>
</tr>
<tr>
<td>Years in school</td>
<td>14.19 (4.00)</td>
<td></td>
</tr>
<tr>
<td>Working for pay</td>
<td>213 (53)</td>
<td></td>
</tr>
<tr>
<td>**Place of birth *</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Canada/U.S.</td>
<td>328 (81)</td>
<td></td>
</tr>
<tr>
<td>Europe</td>
<td>69 (17)</td>
<td></td>
</tr>
<tr>
<td>Asia</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>6 (2)</td>
<td></td>
</tr>
<tr>
<td>Immigrants *</td>
<td>73 (19)</td>
<td></td>
</tr>
<tr>
<td># Years lived in Canada *</td>
<td>40.47 (15.26)</td>
<td></td>
</tr>
<tr>
<td><strong>Disease and treatment information</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Months since diagnosis</td>
<td>37.12 (47.40)</td>
<td></td>
</tr>
<tr>
<td>Advanced cancer</td>
<td>122 (44)</td>
<td></td>
</tr>
<tr>
<td># Current symptoms</td>
<td>4.83 (3.88)</td>
<td></td>
</tr>
</tbody>
</table>

* \(p < .05\)

*Note:* # current symptoms were measured by a modified version of the Memorial Sloan-Kettering Symptom Assessment Scale (MSAS) [160]
Table 2. Confirmatory factor analysis fit indices for the three ICS models tested in data collected from Western-born Caucasians and Chinese immigrants with HNC

<table>
<thead>
<tr>
<th></th>
<th>Western-born Caucasians</th>
<th>Chinese immigrants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4-factor</td>
<td>3-factor</td>
</tr>
<tr>
<td>$SB\chi^2$</td>
<td>259.27,</td>
<td>287.91,</td>
</tr>
<tr>
<td>df</td>
<td>98</td>
<td>101</td>
</tr>
<tr>
<td>$(SB\chi^2/df)$</td>
<td>(2.65)</td>
<td>(2.85)</td>
</tr>
<tr>
<td>NNFI$^{\text{rob}}$</td>
<td>.82</td>
<td>.80</td>
</tr>
<tr>
<td>CFI$^{\text{rob}}$</td>
<td>.86</td>
<td>.83</td>
</tr>
<tr>
<td>AGFI</td>
<td>.87</td>
<td>.86</td>
</tr>
<tr>
<td>SRMR</td>
<td>.08</td>
<td>.08</td>
</tr>
<tr>
<td>RMSEA$^{\text{rob}}$</td>
<td>.06</td>
<td>.07</td>
</tr>
<tr>
<td>$(\text{CI}_{95})$</td>
<td>(.05, .07)</td>
<td>(.06, .08)</td>
</tr>
</tbody>
</table>

Note: 4-factor model (VI, HI, VC, and HC); 3-factor model (VI, HI, COL); and 2-factor model (IND and COL)

Note: $SB\chi^2 =$ Satorra-Bentler scaled $\chi^2$; df = degrees of freedom; NNFI = Bentler-Bonett non-normed fit index; $^{\text{rob}}$ = robust fit index, corrected for non-normal data; CFI = comparative fit index; AGFI = adjusted goodness-of-fit index; SRMR = standardized root mean-square residual; RMSEA = root mean-square error of approximation; $\text{CI}_{95}$ = 95% confidence interval
<table>
<thead>
<tr>
<th>Item</th>
<th>Western-born Caucasian</th>
<th>Chinese immigrant</th>
</tr>
</thead>
<tbody>
<tr>
<td>If a coworker gets a prize, I would feel proud. <strong>HC</strong></td>
<td>.765&lt;sup&gt;a&lt;/sup&gt;</td>
<td>.839&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>The well-being of my coworkers is important to me. <strong>HC</strong></td>
<td>.676&lt;sup&gt;a&lt;/sup&gt;</td>
<td>.575&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>I feel good when I cooperate with others. <strong>HC</strong></td>
<td>.564</td>
<td>.736 .382</td>
</tr>
<tr>
<td>It is important to me that I respect decisions made by my groups. <strong>VC</strong></td>
<td>.563</td>
<td>.641 .478</td>
</tr>
<tr>
<td>To me, happiness is sharing time with others. <strong>HC</strong></td>
<td>.473</td>
<td>.529 .472</td>
</tr>
<tr>
<td>It is important that I perform my job better than others. <strong>VI</strong></td>
<td>.776&lt;sup&gt;b&lt;/sup&gt;</td>
<td>.526&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Winning is everything. <strong>VI</strong></td>
<td>.589&lt;sup&gt;b&lt;/sup&gt;</td>
<td>.506&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Competition is the law of nature. <strong>VI</strong></td>
<td>.563</td>
<td>.324</td>
</tr>
<tr>
<td>When another person does better than I do, I get tense and feel challenged. <strong>VI</strong></td>
<td>.513&lt;sup&gt;b&lt;/sup&gt;</td>
<td>.622&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Family members should stick together, no matter what sacrifices are required. <strong>VC</strong></td>
<td>.670&lt;sup&gt;c&lt;/sup&gt;</td>
<td>.684&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>Parents and children must stay together as much as possible. <strong>VC</strong></td>
<td>.614&lt;sup&gt;c&lt;/sup&gt;</td>
<td>.702&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>Item</td>
<td>Western-born Caucasian</td>
<td>Chinese immigrant</td>
</tr>
<tr>
<td>---------------------------------------------------------------------</td>
<td>------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>It is my duty to take care of my family, even when I have to sacrifice what I want.</td>
<td>.441&lt;sup&gt;c&lt;/sup&gt;</td>
<td>.812&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>I rely on myself most of the time; I rarely rely on others.</td>
<td>.901</td>
<td>.634</td>
</tr>
<tr>
<td>I rather rely on myself than others.</td>
<td>.578</td>
<td>.464</td>
</tr>
<tr>
<td>I often do “my own thing.”</td>
<td>.551</td>
<td>.504</td>
</tr>
<tr>
<td>My personal individuality independent from others is very important to me.</td>
<td>.568</td>
<td></td>
</tr>
</tbody>
</table>

Note: Only factor loadings > .32 were presented.

<sup>VI, HI, VC, HC</sup> Original subscale to which the item belonged; VI = vertical-individualism; HI = horizontal-individualism; VC = vertical-collectivism; HC = horizontal-collectivism

<sup>a,b,c</sup> Factor loading of items with the same superscript are loaded onto the same common factor structure. <sup>a</sup> Items correspond to the factor, Camaraderie with Co-workers; <sup>b</sup> Items correspond to the factor, Competitiveness; <sup>c</sup> Items correspond to the factor, Commitment to Family
Table 4. MSCFA fit indices for the newly derived 8-item, 3-factor measurement model in Western-born Caucasians and Chinese immigrants with HNC

<table>
<thead>
<tr>
<th>MSCFA steps</th>
<th>No constraint (configural invariance)</th>
<th>Factor loadings (weak invariance)</th>
<th>Factor loadings † (partial weak invariance)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SBχ², df (SBχ²/df)</td>
<td>72.72, 32 (2.27)</td>
<td>89.61, 37 (2.42)</td>
<td>76.53, 36 (2.13)</td>
</tr>
<tr>
<td>NNFIrob</td>
<td>.86</td>
<td>.84</td>
<td>.88</td>
</tr>
<tr>
<td>CFIrob</td>
<td>.93</td>
<td>.91</td>
<td>.93</td>
</tr>
<tr>
<td>AGFI</td>
<td>.92</td>
<td>.91</td>
<td>.92</td>
</tr>
<tr>
<td>SRMR</td>
<td>.05</td>
<td>.07</td>
<td>.06</td>
</tr>
<tr>
<td>RMSEArob (CI.95)</td>
<td>.07 (.05, .09)</td>
<td>.07 (.05, .09)</td>
<td>.07 (.05, .09)</td>
</tr>
<tr>
<td>χ² diff (Δχ², Δdf)</td>
<td>---</td>
<td>23.58, 5*</td>
<td>3.81, 4</td>
</tr>
</tbody>
</table>

* p < .05

Note: SBχ² = Satorra-Bentler scaled χ²; df = degrees of freedom; NNFI = Bentler-Bonett non-normed fit index; rob = robust fit index, corrected for non-normal data; CFI = comparative fit index; AGFI = adjusted goodness-of-fit index; SRMR = standardized root mean-square residual; RMSEA = root mean-square error of approximation; CI.95 = 95% confidence interval; χ² diff = χ²-difference test; Δχ², Δdf = difference of χ² and df between current step and the last step that achieved non-significant χ²-difference test.

† Released factor loading equality constrains for the item, “It is my duty to take care of my family, even when I have to sacrifice what I want.” The χ² in this step was compared to the χ² in the no-constrain step.
Table 5. MSCFA fit indices for the newly derived 7-item, 3-factor measurement model in Western-born Caucasians and Chinese immigrants with HNC

<table>
<thead>
<tr>
<th></th>
<th>MSCFA steps</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No constraint</td>
<td>Factor loadings</td>
<td>Item intercepts</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(configural invariance)</td>
<td>(weak invariance)</td>
<td>(strong invariance)</td>
<td></td>
</tr>
<tr>
<td>$\text{SB} \chi^2, df$ (SB$\chi^2$/df)</td>
<td>41.78, 21 (1.99)</td>
<td>47.49, 25 (1.90)</td>
<td>74.46, 29 (2.57)</td>
<td></td>
</tr>
<tr>
<td>NNFI$^{\text{rob}}$</td>
<td>.90</td>
<td>.89</td>
<td>.86</td>
<td></td>
</tr>
<tr>
<td>CFI$^{\text{rob}}$</td>
<td>.96</td>
<td>.95</td>
<td>.93</td>
<td></td>
</tr>
<tr>
<td>AGFI</td>
<td>.94</td>
<td>.93</td>
<td>.91</td>
<td></td>
</tr>
<tr>
<td>SRMR</td>
<td>.05</td>
<td>.06</td>
<td>.09</td>
<td></td>
</tr>
<tr>
<td>RMSEA$^{\text{rob}}$ (CI.95)</td>
<td>.06 (.03, .09)</td>
<td>.07 (.04, .10)</td>
<td>.08 (.05, .10)</td>
<td></td>
</tr>
<tr>
<td>$\chi^2$ diff ($\Delta \chi^2, \Delta df$)</td>
<td>---</td>
<td>5.71, 4</td>
<td>26.97, 4*</td>
<td></td>
</tr>
</tbody>
</table>

* $p < .05$

Note: SB$\chi^2$ = Satorra-Bentler scaled $\chi^2$; df = degrees of freedom; NNFI = Bentler-Bonett non-normed fit index; $^{\text{rob}}$ = robust fit index, corrected for non-normal data; CFI = comparative fit index; AGFI = adjusted goodness-of-fit index; SRMR = standardized root mean-square residual; RMSEA = root mean-square error of approximation; CI.95 = 95% confidence interval; $\chi^2$ diff = $\chi^2$-difference test; $\Delta \chi^2, \Delta df$ = difference of $\chi^2$ and df between current step and the last step that achieved non-significant $\chi^2$-difference test.
Chapter 5
Measuring Culturally Based Values in Adults Living with Chronic and Life-Threatening Disease: Validity of a New Measurement Model for the Individualism-Collectivism Scale in End-Stage Renal Disease, Type 2 Diabetes Mellitus, and Rheumatoid Arthritis

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Manuscript submitted for publication
Abstract

Increasing cultural diversity requires research to inform culturally sensitive, patient-centered care. Individualism and collectivism reflect fundamental psychosocial differences between people from different cultures, but little research examined cultural equivalence of their measures. In this study, we aimed to cross-validate a new 3-factor measurement model (Commitment to Family; Camaraderie with Co-workers; and Competitiveness) derived from the Individualism-Collectivism Scale (ICS) in a previous study. Using data from Caucasians and Chinese with end-stage renal disease, Type 2 diabetes mellitus, and rheumatoid arthritis, we: (a) disconfirmed the original 4-factor ICS measurement model and (b) demonstrated weak invariance in the new 3-factor model. We conclude that the original 4-factor measurement-model does not adequately tap the hypothesized constructs in these samples. Demonstrating weak invariance indicates that the new subscales can be interpreted as equivalent when employed in correlational analyses, providing an alternative method to tap specific, culturally relevant values.

Keywords: measurement invariance, chronic disease, culture, cross-cultural research, individualism-collectivism
Introduction

Chronic disease exerts considerable impact on daily life. Diligent self-management is fundamental to the care plans for many conditions, such as end-stage renal disease (ESRD), Type 2 diabetes mellitus (DM), and rheumatoid arthritis (RA). People affected by ESRD must undergo regular maintenance hemodialysis to filter out waste and fluids from the bloodstream [217]; many with DM require regular blood tests to monitor blood-glucose levels [218]; and those with RA must maintain a balance between exercise and rest to preserve joint function [219]. Maintaining one’s diet is fundamental to self-care for all these conditions. These care tasks can be time-consuming and can interfere with valued activities, compromising psychosocial well-being [44].

The psychosocial impact of chronic disease may vary across culture groups [220]. Among people with ESRD undergoing maintenance hemodialysis, for example, Asians have reported poorer quality of life (QOL) and more social deprivation than white Europeans [221]. Cross-cultural differences in QOL, as assessed by the extent of DM-related limitations and burdens, have also been reported [222]: Hispanic-Americans experience the most difficulties with dietary restrictions and worrying about the future than non-Hispanic Whites, African-Americans, and Asian-Americans; African-Americans experience the most challenges with leisure time flexibility out of all these groups. These cultural variations may arise due to differences in the extent to which people rely on underlying culturally based values to guide their actions and on whether the constraints associated with their diseases conflict with adherence to these values and actions. Culturally based values shape perception, interpretation, affect, and behavior [223,224]. Often, they direct attention to situational aspects of disease or treatment that can make it more difficult to conform to culturally based norms and expectations [79,153]. This, in turn, influences the or interpretation of disease- and treatment-related demands and how people respond to them [152,153].

Individualism (IND) and collectivism (COL) are widely studied cultural syndromes (i.e., sets of culturally based values, attitudes, and beliefs that center around a common theme [79]) that provide a useful theoretical framework within which to understand the effects of culture. These cultural syndromes differentiate the ways in which groups of individuals define the self, how they prioritize relationships, and the types of goals to be pursued [78,79]. IND defines the self as
an independent entity, prioritizes personal goals, and fosters relationships that support their achievement, while COL defines the self in relation to others (i.e., interdependence), emphasizing the value of social harmony and the priorities of group objectives and goals over personal ones [79]. IND and COL can shape cognition, motivation, and behaviour [81], including perceptions of health and disease. People who hold largely individualist values tend to perceive health as intrinsic to their capacity for self-actualization and functioning as an autonomous person [5]. Those who hold largely collectivist views value health, in large part, because it facilitates the ability to fulfill social roles and obligations [5]. These cultural perspectives may help to explain differences in how people from diverse cultural backgrounds react to the same chronic condition.

The Individualism-Collectivism Scale (ICS) [91] is a widely used instrument to tap two sets of cultural syndromes: (a) IND-COL and (b) the vertical-horizontal (VERT-HOR) dimension, which is nested within IND-COL and emphasizes hierarchy and equity in relationships, respectively. The ICS taps four distinct constructs, based on the factorial combination of these cultural syndromes [79,91,93]: vertical-individualism emphasizes improving individual status and distinguishing oneself from others; horizontal-individualism values status equality, self-reliance, and expression of one’s uniqueness; vertical-collectivism is primarily characterized by respect for authority and maintenance of social cohesion, even when self-sacrifice is necessary; and horizontal-collectivism stresses sociability and interdependence with others in an egalitarian social environment.

The ICS has been used to test numerous hypotheses in cultural psychology, including those relating to intergroup negotiations [130] and work relationships [131]. Yet, psychometric studies of the English and translated versions have yielded inconsistent results in terms of measurement invariance—the extent to which the scale items tap the same latent constructs in the same ways across different respondent groups [114]. Measurement invariance is essential in cross-cultural investigations because it rules out two competing hypotheses that threaten the interpretation of observed group differences: that the differences (a) simply reflect measurement error [114,115] or (b) are attributable to systematic error, such as semantic differences between the original and translated versions of a questionnaire [112]. Despite its popularity, the ICS’s 4-factor measurement model has not been consistently replicated. Some results support the original 4-factor ICS measurement model in English and translated versions [74,108], whereas others have
not [133-135]. Moreover, the ICS’s measurement model was developed and validated in healthy, college-student samples [82,91]. It is unclear, therefore, whether the measurement model is generalizable to be used in healthy or chronically ill adult populations.

In the context of an earlier study that examined the ways in which VERT-HOR IND and COL, age, and sex moderate the psychosocial impact of illness-related disruptions to psychologically meaningful activity (i.e., illness intrusiveness [44]) in head and neck cancer (HNC), we used confirmatory factor analysis (CFA) to test the measurement invariance of English and Chinese versions of the ICS in Western-born Caucasians and Chinese immigrants with HNC [225] (for details, see Materials section). Results did not support the original 4-factor model. Using the same data, we subsequently derived a new 3-factor model: (a) Commitment to Family, (b) Camaraderie with Co-workers, and (c) Competitiveness. An initial evaluation of measurement invariance of the new 3-factor model using the same HNC data from which it was derived demonstrated that the measurement model achieved weak invariance [179]; that is, the items’ factor loadings were consistent across Western-born Caucasian and Chinese-immigrant respondent groups.

The cultural factors in this new 3-factor model may be relevant to a number of psychosocial contexts. For example, commitment to family may explain people’s willingness to accept their families’ preferences for non-disclosure of their cancer diagnosis [212] despite the benefits of more open communication [226]. Other family-related values, such as family cohesion—common interests and emotions shared within one’s family—correlate with important patient outcomes, such as self-care adherence, mortality, and QOL, in a wide range of chronic conditions (i.e., RA, DM, ESRD, and cardiovascular disease; for review, see [227]).

In this paper, we aim to replicate and extend our earlier findings by: (a) evaluating goodness-of-fit of the original 4-factor ICS measurement model in three new, independent chronic-disease groups (ESRD, Type 2 DM, and RA); and (b) cross-validating the proposed new 3-factor measurement model in these respondent groups using simultaneous multi-sample CFA (MSCFA). Demonstration of the latter lends support to the generalizability of the new model to other chronic-disease populations, enabling investigators to examine the roles these culturally based values might play in shaping the psychosocial impact of chronic disease.
Methods

Participant Description

The study samples were originally recruited for two independent research studies concerning cultural syndromes and the psychosocial impact of chronic diseases, led by the senior author: (a) self-identified Western-born Caucasians and Chinese immigrants with ESRD or Type 2 DM [Devins et al., unpublished data] and (b) English-speakers with RA [228]. These data provide an opportunity to replicate the measurement invariance findings we observed for the 3-factor model in people with HNC [225]. All respondents were consenting volunteers recruited from teaching hospitals in Toronto, Canada. Each study received approval from our institutional ethics review board.

ESRD and DM Samples

We included only respondents who provided complete ICS data: 206 (79%) people with ESRD and 223 (86%) with Type 2 DM. Included respondents were younger ($M = 59.68; SD = 11.41$) than excluded respondents ($M = 63.34; SD = 11.89$), $t(127) = 2.69$, $p = .008$. A larger proportion of excluded individuals (23.1%) was not working for pay as compared to the percentage of included individuals (3.4%), $\chi^2(1) = 27.72$, $p < .001$.

The ESRD sample included 116 (56%) North American-born and 28 (14%) foreign-born Caucasians, and 62 (30%) Chinese immigrants. The Type 2 DM sample included 69 (31%) North American-born and 21 (9%) foreign-born Caucasians and 133 (60%) Chinese immigrants. Demographic characteristics (see Table 1) did not differ systematically between North American-born and foreign-born Caucasians in either sample, and thus we pooled their responses (hereinafter “Western-born Caucasians”) within respective disease groups.

A minimum ratio of 5:1 participants to items is required to ensure reliable parameter estimates for CFA [113]. Because the ICS [91] contains 16 items, we required a minimum of 80 respondents per group. Our samples did not satisfy this criterion, however (e.g., the Western-born Caucasian Type 2 DM group included only 69 cases, and the Chinese-immigrant ESRD group included only 62). As a result, it was not possible to conduct four separate analyses (i.e., 2 culture groups x 2 disease groups). Thus, we pooled the data across disease groups within
respective culture groups (i.e., Western-born Caucasians with ESRD or Type 2 DM, and Chinese immigrants with ESRD or Type 2 DM). The final sample sizes for each culture group were 185 ESRD-Type 2 DM Western-born Caucasians and 195 ESRD-Type 2 DM Chinese immigrants. Some demographic characteristics differed between the disease groups. Overall, Western-born Caucasians with Type 2 DM were more highly educated than those with ESRD, $\chi^2(5) = 13.51, p = .019$. More Western-born Caucasians with Type 2 DM reported annual household incomes > $75,000, as compared to Western-born Caucasians with ESRD, $\chi^2(5) = 26.98, p < .001$. In both culture groups, more people with Type 2 DM than those with ESRD were working for pay, $\chi^2(1) = 32.50, p < .001$ for Western-born Caucasians and $\chi^2(1) = 7.60, p = .006$ for Chinese immigrants. Among Chinese immigrants, those with DM had a longer history of disease than those with ESRD, $t(193) = 2.95, p = .004$. Collectively, these differences are likely more indicative of disease impact rather than systematic differences in the types of people who develop these conditions: as compared to DM, ESRD (a) requires more intrusive medical treatment (e.g., maintenance dialysis and dietary management versus dietary and activity management only) and (b) typically causes more severe symptoms (e.g., fatigue and cognitive problems) that interfere with work-life [181]. Case-mix differences should be borne in mind when interpreting the results.

RA Sample

The RA sample included 102 (96%) respondents who provided complete ICS data. Included respondents were older ($M = 69.00; SD = 7.35$) than excluded respondents ($M = 56.76; SD = 13.87$), $t(4) = 3.12, p = .037$. The sample consisted of English-speakers born primarily in Canada or the US ($n = 68, 68\%$). Most ($n = 95, 93\%$) reported their ethnicity as either Canadian or a mix of Canadian and European descent (see Table 1 for participant characteristics).

Material

The ICS [91] consists of four subscales (i.e., vertical-individualism, horizontal-individualism, vertical-collectivism, and horizontal-collectivism), each comprising four items. Respondents indicate the extent to which they agree or disagree with each statement using a 9-point bipolar rating scale (1 = “disagree very much,” 9 = “agree very much”). We translated the ICS into Chinese using a standard back-translation protocol [111]. The ESRD-Type 2 DM Western-born
Caucasian and RA samples completed the English version; the ESRD-Type 2 DM Chinese-immigrant sample completed the Chinese version.

In a previous study, we conducted separate CFAs to test the original 4-factor structure using data collected from Western-born Caucasians and Chinese immigrants with HNC [225]. We used the following goodness-of-fit criteria to evaluate model fit [113,165]: Satorra-Bentler (SB) scaled \( \chi^2/df \) ratio, non-normed fit index (NNFI), comparative fit index (CFI), adjusted goodness-of-fit index (AGFI), standardized root mean squared residual (SRMR), and root mean-square error of approximation (RMSEA). Robust fit indices were used since they adjust for non-normally distributed data [165]. We defined “excellent” model fit as SB \( \chi^2/df < 2.0 \), NNFI, CFA, and AGFI > .90, and SRMR and RMSEA \( \leq .08 \) [113,165]. The 4-factor model approached excellent fit when tested in Western-born Caucasians (SB \( \chi^2/df = 2.65 \); NNFI\text{rob} = .82; CFI\text{rob} = .86; AGFI = .87; SRMR = .08; RMSEA\text{rob} = .06), but not in Chinese immigrants (SB \( \chi^2/df = 1.90 \); NNFI\text{rob} = .69; CFI\text{rob} = .76; AGFI = .73; SRMR = .11; RMSEA\text{rob} = .09). Thus, we did not proceed to examine between-group measurement invariance.

We then attempted to identity an alternative common factor structure for Western-born Caucasians and Chinese immigrants with HNC. We employed exploratory factor analysis (EFA), with varimax rotation, to extract a new measurement model using the HNC data [225]. Results indicated a 5-factor solution for Western-born Caucasians and a 3-factor solution for Chinese immigrants. We applied a novel approach to create a common factor structure: we selected items that loaded on the same factors in both Western-born Caucasians and Chinese immigrants to create three new subscales. This resulted in three new factors represented by seven ICS items: (a) Camaraderie with Co-workers (2 items), which emphasizes concern for co-workers’ well-being; (b) Commitment to Family (2 items), which values dedication to ensuring family well-being, including making self-sacrifices to achieve this when necessary; and (c) Competitiveness (3 items), which emphasizes outperforming others in competitive contexts. We subsequently conducted an initial evaluation of measurement invariance of the new 3-factor model, using the HNC Western-born Caucasian and Chinese immigrant data from which the model was derived. The model demonstrated weak invariance (SB \( \chi^2/df = 1.90 \); NNFI\text{rob} = .89; CFI\text{rob} = .95; AGFI = .93; SRMR = .06; RMSEA\text{rob} = .07). This means that factor loadings are identical between the two respondent groups, but the item intercepts are not. Thus, the items can be interpreted as
tapping the same latent constructs in the same ways in both Western-born Caucasians and Chinese immigrants with HNC, but latent-score comparisons may not be valid [114,176].

**Statistical Methods**

We applied the same statistical procedures used in our earlier HNC study to test the model fit of the original ICS and the proposed, new 3-factor measurement models in the ESRD, DM, and RA samples.

**Testing Model Fit of the Original ICS Models**

We conducted CFAs to evaluate the original 4-factor ICS model [91], as well as an alternative 3-factor (VI, HI, and COL) model [82] and a 2-factor (IND and COL) model [80]. We used EQS (version 6.1) to test each model separately on the data from ESRD-Type 2 DM Western-born Caucasians, ESRD-Type 2 DM Chinese immigrants, and English-speakers with RA. We adopted the same goodness-of-fit criteria as in our earlier HNC study [113,165]. We planned to proceed to test between-group measurement invariance next if any model(s) showed excellent fit.

**Assessing Measurement Invariance of New 3-Factor Model**

We tested the measurement invariance of the new 3-factor model. We first performed CFAs for each of the three disease groups separately to evaluate individual model fit. After observing a good fit within groups (contact corresponding author for results), we proceeded to MSCFA, a rigorous, multi-step evaluation that tests fit of the model to the data from all three groups simultaneously. We employed a means and covariance structure analysis (MACS) in the MSCFA [164]. This approach tests increasingly rigorous, hierarchical levels of invariance: (a) configural invariance (the basic factor structure is equivalent across groups); (b) weak invariance (configural invariance is met and the factor loadings are equivalent); (c) strong invariance (weak invariance is met and the item intercepts are equivalent); and (d) strict invariance (strong invariance is met and the item error variances are equivalent; [164]. The established level of invariance indicates the extent to which valid interpretations and syntheses of test scores can be made across respondent groups. An instrument demonstrating strong or strict invariance allows for valid group-mean comparisons of latent variables [164], whereas weak invariance permits valid pooling of data across groups to estimate correlation among variables [114,176].
We first evaluated configural invariance. If configural invariance was met, we then determined the highest level of invariance that characterized the measurement model across the three disease groups. We sequentially added equality constraints that hypothesize the equivalence of a set of parameters across the groups; the first set of equality constraints to test invariance of factor loadings, the next set to test invariance of item intercepts, and the final set to test invariance of item error variances. Invariance is supported when (a) a $\chi^2$-difference test shows non-significant change (i.e., $p > .05$) in $\chi^2$ between the current model with the added equality constraints and the preceding one without them [164] and (b) goodness-of-fit criteria meet or exceed established critical values [113,165]. The model must demonstrate cross-group invariance at the current level of invariance before proceeding to test the next level. Lagrange Multiplier (LM) tests identified post-hoc model modifications to improve goodness-of-fit [179].

Results

Model Fit of the Original ICS Models

CFA findings indicated that the original ICS 4-factor and the alternative ICS models did not provide a good fit to the ESRD-Type 2 DM or RA data. Since all analyses reached the same conclusion, we present the CFA results for the 4-factor model only in Table 2.

Measurement Invariance of the New 3-Factor Model

MSCFA results indicated that the new 3-factor model achieved configural invariance across all three groups (see Table 3). When we tested the equality constraints for weak invariance, the $\chi^2$-difference test showed a non-significant change in $\chi^2$, indicating that factor loadings were equivalent across groups. We could not achieve strong invariance, however, even after considering LM-recommended post-hoc adjustments. We did not proceed with further invariance testing. Figure 1 reports the final estimates for factor loadings, error variances, and inter-correlations among the three latent factors at the level of weak invariance. All factor loadings were significant at $p < .05$.

When we estimated subscale reliabilities, Cronbach’s $\alpha$s were below the recommended criterion of .70 [118] for a number of subscales in the ESRD-Type 2 DM Western-born Caucasian and Chinese immigrant groups and the RA group (Camaraderie with Co-workers = .72, .50, and .62;
Commitment to Family = .61, .56, and .69; and Competitiveness = .60, .61, and .64, respectively).

Discussion

The first goal of this paper was to test whether the original ICS measurement model provides a good fit for data from adult Western-born Caucasians and Chinese immigrants with ESRD or Type 2 DM, and English-speaking adults with RA. Neither the original 4-factor measurement model nor alternative 2- and 3-factor models fit well with data from any of the groups. Given these observations and our earlier findings in HNC [225], we conclude that the ICS does not tap VERT-HOR IND and COL as originally specified, at least in Western-born Caucasians and Chinese immigrants with diverse chronic conditions.

Failure to replicate the originally hypothesized measurement model does not, however, negate the conceptual usefulness of VERT-HOR IND and COL in explaining fundamental cultural differences in chronic illness experience. These cultural syndromes are broad, overarching themes that are difficult to tap using relatively few items [82]. It is also difficult to detect specific associations on the basis of global measurement instruments [229]. Further work on refining their measurement is required (e.g., [133]). On the other hand, overarching cultural syndromes facilitate knowledge synthesis across studies and recognition of broad implications [78,81]. VERT-HOR IND and COL are useful, unifying constructs that integrate a large number of related cultural values. These cultural syndromes comprise multiple elements (e.g., autonomy versus interdependence; personal achievement versus collective goals). In fact, IND and COL comprise more than 60 different facets [79]. Testing associations between specific underlying elements of VERT-HOR IND-COL and psychosocial processes allows us to detect stronger effects. Tension between reliance on global versus specific measurement has been addressed in other areas; for example, the literature on coping illustrates well the use of theoretical (e.g., emotion-focused coping) versus concrete conceptualizations (e.g., engaging in distracting activities; for review, see [230]).

The second goal of the present paper was to cross-validate the new 3-factor ICS measurement model (i.e., camaraderie with co-workers, commitment to family, and competitiveness) that we derived from previous observations in HNC. Our earlier study indicated that this model was
equivalent between culture groups at the level of weak invariance [225], and we observed the same result in the three independent disease groups examined in the current study. Although further evaluation of their construct validity is needed, the three new constructs relate to the broader IND-COL framework. Competitiveness, for example, reflects a central element of vertical-individualism [91]. Duty to one’s in-group (e.g., family) has been associated with COL [78]. People with stronger collectivist values tend to develop high-quality co-worker relationships [131]. The identification of these three cultural constructs complements the call to employ specific and conceptually independent elements of IND-COL in cross-cultural research [71,78]. This strategy should help to minimize construct contamination.

The three constructs may help to explain cross-cultural differences in the experience of chronic diseases. For example, both commitment to family and camaraderie with co-workers may explain cross-cultural differences in willingness to disclose information about one’s diagnosis and prognosis to family and co-workers [212,231]. Commitment to family may help predict the extent to which people with cancer will be concerned about the effects of the disease on their children [204]. Camaraderie with co-workers may help to explain decisions to continue working when people must contend with ESRD or RA [232]. Reduced work-related ambitions [233] and increased rates of withdrawal from work-life post-diagnosis [234] may be associated with reduced Competitiveness.

The present research demonstrates that the factor loadings for the seven items that represent the new 3-factor model are identical when examined in people with ESRD, Type 2 DM, and RA. This finding corroborates the potential of the new subscales in cross-cultural research involving people affected by chronic, disabling, and life-threatening conditions. These values are likely universal but the extent to which they are endorsed can be affected by the experience of serious disease. An example is the experience of post-traumatic growth in people with cancer (see Tedeschi and Calhoun [235] for review). Common changes include the reorganization of priorities and greater appreciation of life [236]. Although disease-related changes would manifest as different scores on subscales designed to tap such phenomena, neither the theoretical meaning of the constructs under consideration nor the underlying factor structure of the instrument(s) designed to measure them should be altered.
Before concluding, we must acknowledge study limitations. First, we employed convenience samples of people with chronic diseases to test the measurement invariance of the ICS, introducing the possibility that idiosyncratic sampling differences may threaten the validity of the results. Because the findings are consistent across diverse disease groups, however, it is unlikely that sampling idiosyncrasies introduced systematic bias. Second, we combined the ESRD and Type 2 DM samples within respective culture groups due to sample-size limitations. Systematic differences in demographic (e.g., education or employment status) and disease characteristics between the ESRD and DM samples may have compromised our effort to achieve strong invariance. Model fit of the new 3-factor model should be cross-validated in separate samples of people with ESRD and DM to test this possibility. Finally, many subscales did not always satisfy minimum reliability criteria across groups. This may be due to the small numbers of items within subscales. Authorities suggest that it is preferable to emphasize model fit over internal consistency at the initial stages of cross-validation, because a poor-fitting model can inflate Cronbach’s $\alpha$ by violating the uncorrelated-error assumption [237]; models that fit well do not do this. We encourage other researchers to develop and evaluate additional items for each of the subscales to bolster subscale reliability.

Conclusions and Implications

The VERT-HOR IND and COL theoretical framework [79] has contributed invaluably to our conceptual understanding of culture, attitudes, values, and practices. The ICS [91] has not, however, consistently demonstrated strong psychometric properties. Our findings failed to support the 4-factor ICS measurement model in people with diverse chronic diseases. The alternative 3-factor structure we proposed identifies relevant constructs that tap more specific culturally based values. The scales are characterized by weak invariance indicates data across Caucasian and Chinese respondents with different medical conditions can be combined for correlational research. Further measurement refinement remains to be done, but the newly derived model may offer a valuable alternative for researchers to understand the psychosocial influence of cultural values. We hope that others will test and employ this new measurement model to inform their own research and to extend knowledge about the ways in which culture shapes the experience and impact of illness.
**Figure Caption**

*Figure 1. The new 3-factor measurement model at the level of weak invariance in Western-born Caucasians and Chinese immigrants with ESRD or DM and English-speakers with RA.* This figure reports the final standardized parameter estimates for the factor loadings, error variances, and inter-correlations for the 3-factor structure. The factor structure is illustrated by the three factors and solid-arrow regression lines pointing to their respective items. These arrows reflect the regression of the items on their respective factors (i.e., factor loadings). The latent factor intercepts are represented by the open-arrow dashed regression lines pointing from the Constant to each factor. A post-hoc adjustment for the ESRD-Type 2 DM Western-born Caucasians is represented by open-arrow dash-dotted regression lines, pointing from a factor to an item. The three factors’ disturbances are permitted to correlate among each other. Because strong invariance was not evident, regression lines associated with item intercepts have been excluded to facilitate interpretation. Each parameter value is reported in the following order: ESRD-Type 2 DM Western-born Caucasians, ESRD-Type 2 DM Chinese immigrants, and English-speakers with RA.
Table 1. Participant characteristics for ESRD, DM, and RA respondents

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>ESRD ($n = 206$)</th>
<th>DM ($n = 223$)</th>
<th>RA ($n = 102$)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$n$ (%)</td>
<td>$M$ (SD)</td>
<td>$n$ (%)</td>
</tr>
<tr>
<td><strong>Demographics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>59.61 (12.79)</td>
<td>59.74 (9.99)</td>
<td>56.76 (13.86)</td>
</tr>
<tr>
<td>Men</td>
<td>114 (55)</td>
<td>116 (52)</td>
<td>40 (39)</td>
</tr>
<tr>
<td>Married</td>
<td>131 (64)</td>
<td>170 (76)</td>
<td>71 (70)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary school</td>
<td>27 (13)</td>
<td>30 (13)</td>
<td>7 (7)</td>
</tr>
<tr>
<td>Secondary school</td>
<td>81 (40)</td>
<td>84 (38)</td>
<td>44 (44)</td>
</tr>
<tr>
<td>Post-secondary</td>
<td>97 (47)</td>
<td>109 (49)</td>
<td>50 (50)</td>
</tr>
<tr>
<td>Working for pay</td>
<td>39 (19)</td>
<td>101 (45)</td>
<td>37 (37)</td>
</tr>
<tr>
<td><strong>Place of birth</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Canada/U.S.</td>
<td>116 (65)</td>
<td>69 (34)</td>
<td>68 (68)</td>
</tr>
<tr>
<td>Europe</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>27 (27)</td>
</tr>
<tr>
<td>Asia</td>
<td>62 (35)</td>
<td>133 (66)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Other</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>5 (5)</td>
</tr>
<tr>
<td>Immigrants</td>
<td>90 (44)</td>
<td>154 (69)</td>
<td>35 (35)</td>
</tr>
<tr>
<td>Years lived in Canada</td>
<td>32.19 (20.11)</td>
<td>22.06 (15.76)</td>
<td>20.86 (10.57)</td>
</tr>
<tr>
<td><strong>Disease and treatment information</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years since diagnosis</td>
<td>8.96 (9.30)</td>
<td>10.97 (8.20)</td>
<td>16.63 (10.89)</td>
</tr>
<tr>
<td>Disease severity *</td>
<td>1.24 (.68)</td>
<td>.68 (.81)</td>
<td>1.40 (.89)</td>
</tr>
</tbody>
</table>

*Note: Some of the categories may not sum to the group $n$ due to missing data.
* The Renal Disease Severity Index (ESRD-SI) [238] measures the respondents’ adjustment to ESRD; the Diabetes Mellitus Severity Index (DM-SI) was adopted from ESRD-SI to measure respondents’ adjustment to DM; the Health Assessment Questionnaire (HAQ) [239] used to measure self-report outcomes of RA. For all of these scales, higher scores reflect worse adjustment or greater disability.
Table 2. Confirmatory factor analysis fit indices of the original 4-factor model of VERT-HOR IND and COL based on a sample of Western-born Caucasian and Chinese immigrant adults with ESRD or Type 2 DM and English-speaking adults with RA

<table>
<thead>
<tr>
<th>ESRD-Type 2 DM</th>
<th>RA</th>
<th>Western-born Caucasians</th>
<th>Chinese immigrants</th>
<th>(n = 102)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SB$\chi^2$, df (SB$\chi^2$/df)</td>
<td>237.45, 98 (2.42)</td>
<td>170.89, 98 (1.74)</td>
<td>146.65, 98 (1.50)</td>
<td></td>
</tr>
<tr>
<td>NNFI$^{\text{rob}}$</td>
<td>.71</td>
<td>.79</td>
<td>.78</td>
<td></td>
</tr>
<tr>
<td>CFI$^{\text{rob}}$</td>
<td>.77</td>
<td>.83</td>
<td>.83</td>
<td></td>
</tr>
<tr>
<td>AGFI</td>
<td>.81</td>
<td>.83</td>
<td>.77</td>
<td></td>
</tr>
<tr>
<td>SRMR</td>
<td>.10</td>
<td>.90</td>
<td>.10</td>
<td></td>
</tr>
<tr>
<td>RMSEA$^{\text{rob}}$ (CI_{95})</td>
<td>.08 (.07, .09)</td>
<td>.06 (.05, .08)</td>
<td>.07 (.05, .09)</td>
<td></td>
</tr>
</tbody>
</table>

Note: SB$\chi^2$ = Satorra-Bentler scaled $\chi^2$; NNFI = Bentler-Bonett non-normed fit index; $^{\text{rob}}$ = robust fit index, corrected for non-normal data; CFI = comparative fit index; AGFI = adjusted goodness-of-fit index; SRMR = standardized root mean-square residual; RMSEA = root mean-square error of approximation; CI_{95} = 95% confidence interval

Note: The 2- and 3-factor models were also evaluated, but neither model met the goodness-of-fit criteria in all three samples (results not shown).
Table 3. Evaluating measurement invariance of the factor structure of the new 3-factor measurement model in Western-born Caucasians and Chinese immigrants with ESRD-Type 2 DM and English-speakers with RA

<table>
<thead>
<tr>
<th>MSCFA step</th>
<th>No parameter constraints (configural invariance)</th>
<th>Factor loadings (weak invariance)</th>
<th>Item intercepts (strong invariance)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SBχ², df (SBχ²/df)</td>
<td>44.18, 32 (1.38)</td>
<td>53.49, 40 (1.34)</td>
<td>127.00, 48 (2.65)</td>
</tr>
<tr>
<td>NNFIrob</td>
<td>.93</td>
<td>.94</td>
<td>.84</td>
</tr>
<tr>
<td>CFIrob</td>
<td>.97</td>
<td>.97</td>
<td>.92</td>
</tr>
<tr>
<td>AGFI</td>
<td>.93</td>
<td>.94</td>
<td>.91</td>
</tr>
<tr>
<td>SRMR</td>
<td>.05</td>
<td>.05</td>
<td>.07</td>
</tr>
<tr>
<td>RMSEArob (CI.95)</td>
<td>.05 (.00, .08)</td>
<td>.04 (.00, .08)</td>
<td>.08 (.05, .10)</td>
</tr>
<tr>
<td>χ²-difference test:</td>
<td>---</td>
<td>9.31, 8</td>
<td>73.51, 8*</td>
</tr>
<tr>
<td>Δχ², Δ df</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* p < .05

Note: SBχ² = Satorra-Bentler scaled χ²; NNFI = Bentler-Bonett non-normed fit index; rob = robust fit index, corrected for non-normal data; CFI = comparative fit index; AGFI = adjusted goodness-of-fit index; SRMR = standardized root mean-square residual; RMSEA = root mean-square error of approximation; CI.95= 95% confidence interval; Δχ², Δ df = difference of χ² and df between current step and the last step that achieved non-significant χ²-difference test.
Chapter 6
Family Commitment and the Appraisal of Cancer Stressors among Adult Western-Born Caucasian and Chinese Immigrant Head and Neck Cancer Survivors


Manuscript submitted for publication
Abstract

Objective: Cancer-related stressors introduce numerous adaptive demands. Culture may shape these experiences by heightening the salience of stressor aspects that most directly threaten culturally endorsed values. We investigated whether the culturally based value of commitment to family influences the interpretation of cancer-related stressors. We hypothesized that (a) adult head and neck cancer (HNC) survivors who strongly endorse commitment to family would interpret cancer-related events as stressful when they threatened opportunities to fulfill family obligations and that (b) culture group would moderate this relation.

Methods: Western-born Caucasian ($n = 196$) and Chinese-immigrant ($n = 44$) HNC survivors were interviewed as a part of a larger study. Respondents reported why they found cancer-related events to be stressful (i.e., “stressor appraisals”). Coders judged whether stressor appraisals reflected threats to commitment to family. Adherence to the value of commitment to family was tapped by a culturally-equivalent Commitment to Family scale.

Results: Controlling for sex, culture group, education, and treatment complexity, hierarchical Poisson regression analysis indicated a significant Culture Group x Commitment to Family interaction ($p = .045$): in Chinese immigrants, strong commitment to family was associated with appraising cancer-related events as threatening the ability to fulfill commitment to one’s family. This was not evident in Western-born Caucasians.

Conclusions: Commitment to family likely primes people to interpret cancer-related events as stressful when they construe them as threatening this central, culturally based value. Attention to such factors can help clinicians to provide more effective, culturally sensitive patient-centered care.

Keywords: head and neck cancer, values, appraisal, stress and coping, culture
Introduction

Attention to culture is fundamental to patient-centered care [73]. Culture shapes explanatory models of disease [6,8], identifies distressing symptoms [9], and influences illness perception and description [6,10]. Cultural effects are especially evident when a disease, such as head and neck cancer (HNC), is prevalent in diverse ethnic groups.

HNC is the sixth most common cancer [17], with the highest incidences in Southern Asia and Europe [14]. Many with HNC experience side effects and dysfunctions, such as dry mouth and swallowing difficulties [28,30]. Some people are disfigured [240]. These effects introduce profound adaptive challenges because they interfere with participation in meaningful activities, such as caregiving [32,42,44] and social exchange [35,240].

HNC presents numerous stressors [41], but why they are stressful may vary across individuals. We believe the appraisal of HNC-related stressors is shaped by cultural values [5,220]. These values reflect the importance people invest in various aspects of life (e.g., relationships) [152,153]. When cancer-related events threaten the ability to fulfill central values, people tend to interpret them as stressful. Hence, exposure to such stressors elicits more worry and concerns than exposure to stressors that either threaten less-central values or do not threaten any at all [152,153].

Because culture shapes fundamental values, people from different cultures may experience a given situation as stressful for different reasons and to different degrees [69,241]. Evidence supports this assertion. For example, people’s worries reflect their values. One study [153] examined two types of values: (a) self-enhancement (emphasizing power, personal achievement, and pleasure) and (b) self-transcendence (emphasizing the welfare of all people and nature). Self-enhancement values were associated with worries about oneself, close friends, and family, whereas self-transcendent values were associated with worries about the wider world or society [153]. Observed relations between self-construal and illness concerns also provide support [12]: independent self-construal (i.e., self as an autonomous entity) is associated with perception of disease as a personal concern, whereas interdependent self-construals (i.e., self conceptualized in terms of relationships with others) relate to perception of disease as a social concern [12].

Priming studies indicate that people adopt psychosocial perspectives consistent with cued
cultural constructs [76]. When individualism is primed, people are more likely to endorse congruent values (e.g., independence) and less likely to emphasize social relationships or obligations. Evidence, to date, is based on culturally homogeneous, healthy groups. If we can replicate the findings that cultural values influence people’s perceptions in the context of cancer, this may offer new insights into cross-cultural variations in cancer experiences.

The present study examined hypothesized relations between culturally based values and the appraisal of cancer-related events. As part of a study concerning the psychosocial impact of cancer-induced lifestyle disruptions, we measured “commitment to family”—dedication and willingness to make self-sacrifices in the service of family well-being [225]. We hypothesized that people with cancer for whom commitment to family is a central value will more likely appraise cancer-related events as stressful when they believe the events threaten their abilities to fulfill family responsibilities. We hypothesized that this would be less likely to occur when people are less committed to this value.

All people may feel obliged to sacrifice for the well-being of their families, but the extent may differ across culture groups. People from Western cultures, for example, tend to consider the fulfillment of family commitments as voluntary (i.e., at one’s discretion), whereas people from Chinese cultures tend to construe this as a duty (i.e., as obligatory without exception) [78,123]. Evidence to support this distinction was reported in a study concerning cancer worries in women with dysplasia, breast or cervical cancer [67,68]: Caucasian women worried primarily about incapacitation and the loss of autonomy, whereas Asian-American women were concerned mainly with cancer’s impact on their families and their abilities to fulfill the caregiver role. We, therefore, hypothesize that the association between commitment to family and stressor appraisals that reflect threats to this value will be more evident in Chinese immigrants with HNC than in their Western-born Caucasian counterparts.

We cannot manipulate respondent characteristics to rule out competing explanations in naturalistic research. An alternative approach is to conduct statistical analyses to test plausible competing hypotheses. If none of the competing factors significantly moderates the hypothesized relation, we can be more confident about our interpretations. For this study, we tested the competing hypotheses that sex (a proxy for gender [199]), age (a proxy for life stage [200]), and proportion of life lived in Canada (a proxy for acculturation [201]) moderate the relation between
commitment to family and the appraisals of cancer-related stressors as threatening to this cultural value. Evidence suggests that the meaning of family and one’s role within it vary depending on one’s gender, life stage, and acculturation. Women tend to be more sensitive to negative events that affect their family than men [202,203]. The meaning of family and familial responsibilities changes over the lifespan as a function of shifting familial roles (e.g., dependent, parent, and grandparent) [200]. Those who are acculturated tend to adopt certain cultural values of the host country (e.g., fulfillment of familial responsibilities as voluntary tasks [78,206]) to a greater extent than those who are not acculturated [207].

Methods

Participant Recruitment

The parent study recruited 418 Western-born Caucasian and 121 Chinese-immigrant HNC survivors who met the following criteria: (a) age 18 years or older; (b) undergoing post-curative treatment follow-up; and (c) fluent in English, Cantonese, and/or Mandarin.

Research staff approached prospective participants at the HNC clinic at a university-affiliated, tertiary cancer-center in Toronto, Canada. We collected demographic information from those who declined or withdrew to evaluate selection bias. The study received ethics approval.

Materials

We translated the English materials into Chinese using a standard back-translation method [111].

Commitment to Family Scale

We used a 2-item Commitment to Family scale, derived from the Individualism-Collectivism Scale (ICS) [91]. It measures one’s dedication to family well-being and willingness to make self-sacrifices toward this end [225]. The scale demonstrated weak invariance in Chinese and Caucasian samples with chronic illness, which means that scores can be interpreted as structurally equivalent when interpreting correlations between the concept and other variables [225,242]. The items include “Family members should stick together, no matter what sacrifices are required” and “Parents and children must stay together, as much as possible.” Respondents indicate agreement or disagreement with each statement using a 9-point rating-scale (1 =
disagree very much; 9 = agree very much). High scores reflect strong commitment to family. Cronbach’s $\alpha = .64$ and .76 for the Western-born Caucasian and Chinese-immigrant samples, respectively.

**Cancer-Related Stressor Checklist (CRSC)**

The CRSC documents exposure to common cancer-related stressors [243]. It comprises eight categories, each with three items: disease and treatment factors; existential threats; interference with activities; interpersonal issues; lack of information; stigma; subjective distress; and uncertainty. Respondents identify stressors that have occurred during their cancer experience. High counts reflect high stressor burden.

We appended an open-ended question—“What is the most stressful part about [this] for you?”—to each CRSC item to tap why respondents experienced the event as stressful. We labeled these responses, “stressor appraisals.” To maximize measurement coverage while minimizing response burden, we created three CRSC versions. Each version included one item from each CRSC category. Thus, each respondent was asked to provide a stressor appraisal for eight (rather than all 24) CRSC stressors. Respondents were randomly assigned to receive one of the parallel versions, with the qualification that equal numbers of versions be administered across the entire sample.

**Demographic and clinical information**

We used a demographic questionnaire to record respondent characteristics. Clinical information was obtained by self-report and from the Ontario Cancer Registry. We used the modified Memorial Sloan-Kettering Symptom Assessment Scale [159] to tap symptom burden. This version excluded items that overlap with psychological symptoms (e.g., difficulty concentrating) or symptom-distress ratings [244].

**Procedures**

Interviewers administered the questionnaires in English, Cantonese, or Mandarin. Participants received modest compensation ($20). We audio-taped responses to the open-ended questions about stressor appraisals. Bilingual research personnel transcribed the responses verbatim and
translated non-English transcripts into English. The first author verified all translations and resolved any substantive variations with bilingual research personnel.

**Statistical Methods**

We conducted data analyses in two stages. First, we identified and tabulated (within respondents) appraisals reflecting threats to commitment to family. Second, we used hierarchical Poisson regression to test the hypothesis that endorsement of commitment to family is associated with a tendency to identify stressor appraisals that reflect threats to the ability to fulfill family obligations.

Post-hoc sample size estimation indicated that 240 cases \((d = 0.30, \alpha = 0.05, \text{ and power } = 0.90)\) were required to achieve adequate statistical power [182]. We select 80 transcripts from each of the three CRSC versions that contained at least one codeable “stressor appraisal” response for each CRSC item. This maximized the data available for analysis. Of the 240 transcripts, 187 (78%) contained at least one codeable response for seven of the eight items.

**Coding Stressor Appraisals that Reflect Threats to Commitments to Family**

We extracted stressor appraisals from interview transcripts before identifying those that reflected threats to commitment to family. Members of our multidisciplinary team independently identified excerpts in all transcripts that contained a stressor appraisal. The team reached consensus about the presence of stressor appraisals, then assigned unique appraisal categories a label and definition. Excerpts reflecting the same stressor appraisal were coded under the same category. The number of excerpts under each stressor-appraisal category reflects the frequency of reporting. In total, we identified 184 stressor appraisal categories (the complete list is available from the corresponding author).

In a subsequent step, we identified the subset of stressor appraisals that reflected threats to commitment to family. We conducted this in two stages. First, we reduced the number of stressor appraisal categories. Two coders independently sorted the 184 stressor-appraisal categories into mutually exclusive groups: (a) appraisals that reflected threats to one of three cultural values
(Commitment to Family, Camaraderie with Co-workers, and Competitiveness) and (b) appraisals that did not reflect threats to any of these values. We subsequently categorized interview excerpts to achieve more specific coding. Coders judged whether the excerpts reflected threats to one or more of the three identified cultural values. For both stages of coding, we estimated inter-rater reliability using Krippendorff’s alpha [186,187], which reflects consistency in applying codes rather than the anticipated distribution of a-priori categories [186].

**Testing the Hypothesis**

We used hierarchical Poisson regression analysis to test the hypothesis because we identified very few stressor appraisals that involved threats to commitment to family [191]. We identified covariates using correlational analyses. We entered empirically identified covariates in the first step of the hierarchical Poisson regression; Culture Group in the second step; Commitment to Family score in the third step, and the Culture Group x Commitment to Family interaction term in the final step. The last step tests the moderating effect of culture group on the association between commitment to family and the reporting of stressor facets that reflect threats to this value [245].

Poisson regression tests logarithmic, rather than linear, relations between the outcome and explanatory variables [191]. We first tested the Poisson-model assumption that the data mean and variance were equal. Type I error is likely when the variance exceeds the mean (i.e., “overdispersion”) [191,192]. To test this assumption, we considered two alternative models that adjust for overdispersion: (a) the overdispersed Poisson regression model and (b) the negative binominal model. Overdispersion is present when: (a) the scaling factor (i.e., the ratio between the deviance and its corresponding degrees of freedom) in the overdispersed Poisson regression model is greater than 1; or (b) the parameter $\alpha$ in the negative binomial model is greater than 0 [191].

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The original intent was to compare each cultural value to its corresponding value-threatening appraisals. Thus, we based the coding of stressor appraisals and interview excerpts on relevance to one of the three cultural values. However, as will be reported in the Results section, we focused on appraisals relating to commitment to family because we did not find any appraisals reflecting threats to either camaraderie with co-workers or competitiveness.
We compared the standard Poisson, overdispersed Poisson, and negative binomial hierarchical models to determine which model best described the data. The overdispersed Poisson and the negative binomial models are not nested models (i.e., the scaling factor and the parameter \( \alpha \) differed for each hierarchical step in the overdispersed Poisson and negative binomial models, respectively). Hence, they cannot be compared directly using the common method of comparing their deviance, which indicates how “poor” the fit is compared to a perfectly fitting model [191,192]. Thus, we compared the Akaike Information Criterion (AIC) and the Bayesian Information Criterion (BIC) across the three models at the same step in the analysis [193]. This approach allowed us to compare nested and non-nested models directly. Lower values indicate better fit.

Once the best-fitting model was identified, we examined the change in deviance between the hierarchical steps [191]. The reduction in deviance from one step to the next reflects the extent of improvement in model fit with the addition of the hypothesized explanatory variables to the regression equation. We used chi-square to test whether observed reductions in deviance were statistically significant. To determine the effect size of reduction in deviance between each hierarchical step, we converted the reduction in deviance (\( \Delta \) deviance) to phi coefficient (\( r_{\phi} \)) [194]. A \( r_{\phi} \) of .10, .30, and .50 reflect small, medium, and large effect size, respectively [195,196]. We plotted significant logarithmic regression findings using a graphic template developed by Dr. Jeremy Dawson [197].

I also tested the slope of each line in the interaction term to determine whether the relation between Commitment to Family and the appraisals that reflect threats to that value was significantly different in the culture groups. Using the method described by Dawson [198], I tested the significance of each slope by referring the ratio between the slope to its standard error to the \( t \) distribution (with a degree of freedom of \( n - k - 1 \), where \( k \) is the number of predictors in the model).

**Testing Competing Hypotheses**

We conducted separate sets of hierarchical Poisson regressions to rule out the effects of other potential moderators (i.e., gender, life stage, and acculturation) on the relation between commitment to family and stressor appraisals that reflect threats to one’s commitment to family. We employed (a) Sex as a proxy for gender [199], (b) Age as a proxy for life stage [200], and (c)
Proportion of Life Lived in Canada (i.e., number of years lived in Canada divided by age) as a proxy for acculturation [201]. We used the same protocol as described above. For example, to test the moderating effect of sex, we entered empirically derived covariates in the first step; Culture Group in the second step; Sex in the third step; 2-way interaction terms (i.e., Culture Group x Commitment to Family and Sex x Commitment to Family) in the fourth step; and the 3-way interaction term (i.e., Sex x Culture Group x Commitment to Family) in the final step. Similar hierarchical Poisson regressions were conducted, substituting Sex for Age and Proportion of Life Lived in Canada separately, to assess their moderation. We calculated $r^2$ for the reduction in deviance to estimate the effect size [194,196].

**Results**

**Participant Characteristics**

Two hundred-forty (45%) respondents’ transcripts were selected from the parent study to maximize the stressor-appraisal data available for analysis. Included respondents were younger ($M = 51.53$, $SD = 12.01$) than the excluded sample ($M = 59.37$, $SD = 11.74$), $t(537) = 7.63$, $p < .001$. A higher proportion of women (52%) was in the included than the excluded sample (33%), $\chi^2(1) = 19.73$, $p < .001$. The final sample included a smaller proportion (18%) of Chinese immigrants than the excluded subsample (26%), $\chi^2(1) = 4.21$, $p = .040$.

Few characteristics differed between Western-born Caucasians ($n = 196$) and Chinese immigrants ($n = 44$; see Table 1). More Western-born Caucasians (51%) reported annual household incomes > $75,000 than Chinese immigrants (21%), $\chi^2(2) = 12.29$, $p = .002$. Among immigrants, Western-born Caucasians ($M = 40.03$ years; $SD = 14.39$) had been living in Canada longer than Chinese immigrants ($M = 17.68$ years; $SD = 11.74$), $t(78) = 7.65$, $p < .001$. No clinical characteristics differed significantly between the groups (see Table 1).

**Commitment to Family and Stressor Appraisals Reflecting Threats to This Value**

The mean Commitment to Family score was $6.68$ ($SD = 1.87$) for Western-born Caucasians and $7.08$ ($SD = 1.85$) for Chinese immigrants. Chinese immigrants reported significantly more stressor appraisals reflecting threats to commitment to family ($M = 0.64$; $SD = 0.87$; range = 0-5) than did Western-born Caucasians ($M = 0.37$; $SD = 0.77$; range = 0-3), $t(238) = 2.01$, $p = .046$. 
Coding of Stressor Appraisals

We first coded the 184 stressor appraisals to determine whether they reflected threats to one of three values (commitment to family, camaraderie with co-workers, and competitiveness). Both coders agreed that 28 (15%) appraisals reflected threats to these values and 118 (64%) did not. They disagreed about the coding of 38 (21%) appraisals. Krippendorff’s alpha was .43, which is lower than recommended (i.e., ≥ .67; [189]). This may be attributable to the subjective nature of the coding process because considerable interpretation was required.

To conduct more specific coding, we categorized the interview excerpts (n = 1225) coded under the 28 stressor appraisals that reflected threats to the cultural values and the 38 appraisals that received discrepant coding. We recoded these to reflect whether they represent threats to one or more of the three specified values. Coders agreed that 105 (9%) excerpts reflected threats to commitment to family; 36 (3%) reflected threats to both commitment to family and camaraderie with co-workers; and 979 (80%) did not reflect threat to any of the values. No excerpt reflected threats to either camaraderie with co-workers or competitiveness. Coders disagreed about the coding of 105 (9%) excerpts. Krippendorff’s alpha was .51. Reliability improved from the previous coding stage, but remained lower than recommended [189]. Two factors may have contributed to this: (a) coders considered the interview excerpts out of context (i.e., they did not receive the entire transcript for each excerpt), which may have made it more difficult to comprehend the meaning of an excerpt and (b) interpretation involved subjectivity, which may have contributed to inconsistencies. To minimize problems due to coding unreliability, we limited subsequent analyses to include only the 105 excerpts agreed upon by coder to reflect threats to commitment to family.

Testing the Hypothesis

We tested the standard Poisson, overdispersed Poisson, and negative binomial models to determine which best fit the data. We concluded that overdispersion was present because the scaling factor and parameter \( \alpha \) were greater than 1 and 0, respectively (see Table 2). We then compared the AIC and BIC values of the three models across the same hierarchical step. The overdispersed Poisson model had the smallest AIC and BIC values out of all three models (see Table 2). Thus, we concluded that the overdispersed Poisson model provided the best fit.
The overdispersed Poisson hierarchical-regression model was employed to test the hypothesized association between commitment to family and stressor appraisals reflecting threats to this value (see Table 3). Empirically identified covariates included sex, education, and treatment complexity. In the first step, results indicated significant main effects for Sex, with women reporting more stressor appraisals representing threats to commitments to family than men \( (B = 0.58; SE = 0.22; p = .010) \). In the second step, the main effect of Culture Group was significant, Chinese immigrants reported more such appraisals than Western-born Caucasians \( (B = 0.57; SE = 0.24; p = .017) \). The reduction in deviance between the first and second steps was small \( (r^2 = .16) \) but significant, \( \chi^2(1) = 5.86, p = .02 \). The main effect for Commitment to Family was not, however, statistically significant \( (B = -0.042; SE = 0.06; p = .447) \). In the final step, we entered the Culture Group x Commitment to Family interaction term to test the moderating effect of culture group on the relation between commitment to family and reported stressor appraisals that reflect threats to commitments to family. The interaction term was statistical significant \( (B = 0.28; SE = 0.14; p = .045) \). The reduction in deviance between the third and fourth steps was small \( (r^2 = .15) \) but significant, \( \chi^2(1) = 5.06, p = .02 \). Figure 1 plots this finding. Among Chinese immigrants with HNC, increasing endorsement of commitment to family was associated with increasing numbers of reported stressor appraisals reflecting threats to this value, but this was not the case for their Western-born Caucasian counterparts. Despite the significant interaction term, the simple slope test indicated that the number of reported stressor appraisals did not differ between individuals with low or high level of Commitment to Family within either culture group.

**Testing Competing Hypotheses**

None of the hypothesized moderators or their corresponding 2- and 3-way interactions was statistically significant (effect sizes: \( r^2 = .02 \) to .12; \( ps > .05 \)), with only one exception. A significant main effect was observed for Sex \( (r^2 = .18; p = .005) \); that is, women were more likely than men to report stressor appraisals reflecting threats to commitment to family. This finding was consistent with the previously observed significant main effect for Sex.

**Discussion**

HNC introduces numerous cancer-related stressors [41]. Why they are stressful depends, in part, on whether they threaten the ability to adhere to important cultural values. In this study, we
investigated whether the value of commitment to family influences the appraisal of HNC-related occurrences as stressful.

We tested whether commitment to family sensitizes people to perceive cancer-related stressors as threatening their abilities to fulfill family obligations. The relation between commitment to family and the tendency to report stressor appraisals that reflect threats to adherence to this value appears to vary slightly, but significantly, between culture groups. Among Chinese immigrant HNC survivors, those who reported higher commitment to family tended to report more stressor appraisals that reflected threats to their abilities to fulfill family commitments than those who endorsed this value to a lesser extent. The relation may be particular to Chinese people because filial piety is a fundamental principle in Chinese culture [246,247]. Chinese undergraduate students, for example, report feeling closer to their families than they feel about their friends [248]. Chinese people tend to feel a stronger sense of obligation to their parents and grandparents than Europeans [249]. Chinese people with cancer may be especially sensitive to the impact of their illness on their families [210] because cancer is often experienced as a “family disease” ([250], p.657).

The immigrant status of our Chinese respondents may also play an important role in the observed interaction effect. Immigrants with HNC must manage cancer-related stressors and adaptive demands of adjusting to a new culture and environment [251,252]. Chinese immigrants often rely on members of their families for emotional support, especially in the case of cancer. This reliance can be attributed to the stigma associated with cancer in the larger community [253], as well as being separated from extended family [252]. Hence, one’s family in the host country becomes the primary source of social support, and this strengthens the bonds and commitment to them. Given these circumstances, it is likely that Chinese immigrant HNC survivors who hold a strong sense of commitment to family will be especially sensitive to cancer-related stressors that may interfere with the ability to fulfill family obligations. Future research should include non-immigrant Chinese (e.g., studies conducted in China; second-generation Chinese-North Americans) to tease out the incremental influence of immigrant status on the relation between commitment to family and appraising HNC as stressful because it threatens this value.

Western-born Caucasian HNC survivors who expressed a strong sense of commitment to family reported fewer stressor appraisals reflecting threats to this value than Asian-born Chinese
immigrants. This may reflect the effort made by Western-born Caucasians to cope with the cognitive dissonance [254] created due to competing priorities. Western-born Caucasians may perceive HNC as a threat to personal independence because they tend to view maintaining good health as a means to actualize autonomy [255]. Despite the importance of familial relations, they tend to view family obligations as something one takes on voluntarily [78]. Thus, when HNC stressors threaten both personal and familial priorities, Western-born Caucasian HNC survivors may be more likely to focus on threats to their autonomy and minimize the effects of HNC stressors on their commitment to family in order to reduce the cognitive dissonance they experienced. Inasmuch as this may also provide the benefit of alleviating feelings of guilt, such selective appraisals may be especially effective in preserving subjective well-being. In the present context, this may have been expressed as a reduction in reported stressor appraisals involving commitment to family. Although we cannot test this hypothesis, cross-cultural studies indirectly support this assertion: Caucasians are more likely to emphasize personal concerns, such as incapacitation and autonomy, than Asians, Hispanics, and African-Americans [67,68]. When asked to identify the stressors they have experienced, European-Americans report more personal stressors (e.g., problems with health, money) than Asians and Asian-Americans [256]. Future studies might fruitfully investigate whether Western-born Caucasians are more likely than Asian-born Chinese to perceive cancer-related stressors as threatening to their independence.

When we compared the slopes of the lines for Western-born Caucasians and Chinese immigrants, the difference was not statistically significant. This may be due to the reliance on a naturalistic study design, which affords dramatically less “relative” statistical power than conventional experimental designs in which jointly extreme values of the explanatory variables are represented in large numbers [257]. The form of the interaction as depicted in Figure 1, however, is consistent with our hypothesis that the relation between commitment to family and recognition of stressor appraisals that reflect threats to that value is in some way different between the two culture groups. It implies that commitment to family may be more strongly related to recognition of such stressors among Chinese immigrants than among Western-born Caucasians. The failure to detect a pattern of results that provides unequivocal support for this interpretation, however, renders further investigation imperative. Collectively, the observed relation depicted in Figure 1 and its consistency with existing knowledge about differences in the
ways culture groups interpret the notion of family commitment are consistent with the working hypothesis that cultural values shape the appraisal of cancer-related stressors.

Each culture maintains a multitude of values and each of these likely influences the ways in which people experience cancer. Focusing on specific cultural values can provide a direct test of the role such factors play in relation to coping and adaptation [81]. Our results suggest, however, that culture of origin may serve as an incremental explanatory variable that captures influences that are not represented by direct measures of specific, cultural values such as the Commitment to Family scale [220]. Existing research in cultural psychology supports this notion. For example, collectivism explained a small, but incremental proportion of the variance in the relation between the sense of independence and college adjustment in Korean students (who come from a predominantly collectivistic culture) [258]. This suggests that college adjustment may be shaped, in part, by aspects of being Korean that are not tapped by the collectivism scale. The inclusion of culture-group membership, in addition to specific culturally based values, may help to identify new explanatory variables and can thereby expand theories. This finding may also reflect a limitation of the Commitment to Family scale we used. With only two items, this scale may not fully encapsulate the concept of commitment to family. As a result, expanding the scale’s coverage of the concept may enhance its explanatory power. Additional items may improve the scale’s ability to detect the relation between commitment to family and the corresponding appraisals.

We tested other potential moderators (i.e., gender, life stage, and acculturation) of the relation between commitment to family and stressor appraisals that reflect threats to that value. Only the main effect of sex was statistically significant: Women with HNC reported these types of appraisals more frequently than men. This pattern is consistent with existing knowledge that family caregiving plays a more central role in women’s lives than men’s. Women attribute greater importance to self-transcendent values (emphasizing the well-being of others) than do men, who tend to place greater emphasis on self-enhancement (e.g., pursuing personal goals and interests) [259]. In contrast to men, women prioritize family roles over work roles [260] and more often identify life changes that negatively impact the family as undesirable as compared to men [202]. Hence, gender may influence the extent to which people appraise cancer-related stressors as threatening their abilities to fulfill commitments to their families. None of the other moderators or the corresponding 2- and 3-way interaction terms was statistically significant. It is
reasonable, therefore, to conclude that these factors do not introduce viable alternative explanations for the study findings.

We must acknowledge some study limitations. First, we asked respondents about their appraisals of cancer-related stressors in general, rather than soliciting appraisals that reflected threats to a particular value. This may explain why we did not detect appraisals that reflected threats relevant to camaraderie with co-workers or competitiveness. Second, other competing hypotheses cannot be ruled out definitively. Our proxy measures for life stage and acculturation (i.e., age and proportion of life lived in Canada) may not capture subtle, but meaningful effects. For instance, proportion of life lived in Canada may not reflect acculturation with sufficient sensitivity because many longtime Chinese immigrants, especially those living in communities with high proportion of Chinese immigrants such as Markham, Ontario, continue to live and interact primarily with people from their own culture. Moreover, other extraneous factors such as family structure may play a role in the hypothesized relations. For example, being responsible for dependents may increase one’s sense of duty to provide care and support, thereby sensitizing people to the ways in which HNC stressors may interfere with fulfilling commitments to their families. The retrospective, cross-sectional study design precludes confirmation of causal priorities between commitment to family and the tendency to appraise cancer-related events as stressful because they threaten commitment to family (e.g., after appraising cancer-related stressors as threatening the ability to fulfill family obligations, people may have endorsed commitment to family to a greater extent than they might have if they had not formulated this appraisal). Finally, the sample was purposefully selected to maximize stressor-appraisal responses available for analysis. Thus, further investigation in other samples is required to establish the generalizability of the findings.

Conclusions

Culture-group membership and culturally based values influence the ways in which people appraise cancer-related stressors. Thus, people may experience the same circumstances as stressful, but for different reasons. Culture shapes cognition, affect, motivation, and behavior. Culturally informed understandings of how people perceive and respond to cancer can facilitate patient-centered care and thereby enhance psychosocial adaptation and well-being.
**Figure Caption**

*Figure 1. Culture Group x Commitment to Family interaction on the number of reported stressor appraisals that reflect threats to commitment to family based on the overdispersed Poisson regression model.* Stronger endorsement of commitment to family is associated with more reports of stressor appraisals reflecting threats to this value among Chinese immigrants with HNC; however, it is associated with fewer reports of these stressors appraisals among Western-born Caucasians with HNC.
**Table 1.** Demographic and clinical characteristics of Western-born Caucasian \((n = 196)\) and Chinese immigrant \((n = 44)\) with HNC

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Western-born Caucasians</th>
<th>Chinese immigrants</th>
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<td></td>
<td>(M (SD))</td>
<td>(n (%))</td>
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<tr>
<td>Education (years)</td>
<td>15 (4)</td>
<td>15 (5)</td>
</tr>
<tr>
<td>Working for pay</td>
<td>118 (60)</td>
<td>21 (48)</td>
</tr>
<tr>
<td># Children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>50 (26)</td>
<td>11 (25)</td>
</tr>
<tr>
<td>1</td>
<td>27 (14)</td>
<td>10 (23)</td>
</tr>
<tr>
<td>2</td>
<td>76 (39)</td>
<td>17 (39)</td>
</tr>
<tr>
<td>3</td>
<td>43 (22)</td>
<td>6 (14)</td>
</tr>
<tr>
<td>Gross household income **</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; $25,000</td>
<td>15 (9)</td>
<td>6 (14)</td>
</tr>
<tr>
<td>$25,000-74,999</td>
<td>70 (40)</td>
<td>27 (64)</td>
</tr>
<tr>
<td>$75,000 = &gt;</td>
<td>90 (51)</td>
<td>9 (21)</td>
</tr>
<tr>
<td>Immigrant **</td>
<td>39 (20)</td>
<td>44 (100)</td>
</tr>
<tr>
<td>Years in Canada **</td>
<td>40 (14)</td>
<td>18 (12)</td>
</tr>
<tr>
<td>Clinical characteristics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Months since diagnosis</td>
<td>29 (31)</td>
<td>31 (39)</td>
</tr>
<tr>
<td>Characteristic</td>
<td>Western-born Caucasians</td>
<td>Chinese immigrants</td>
</tr>
<tr>
<td>------------------------</td>
<td>-------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td></td>
<td>$M$ ($SD$) $n$ (%)</td>
<td>$M$ ($SD$) $n$ (%)</td>
</tr>
<tr>
<td>Cancer stage</td>
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<td></td>
</tr>
<tr>
<td>I</td>
<td>60 (46)</td>
<td>10 (31)</td>
</tr>
<tr>
<td>II</td>
<td>19 (14)</td>
<td>8 (25)</td>
</tr>
<tr>
<td>III</td>
<td>22 (17)</td>
<td>8 (25)</td>
</tr>
<tr>
<td>IV</td>
<td>31 (24)</td>
<td>6 (19)</td>
</tr>
<tr>
<td># Treatment modalities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>23 (12)</td>
<td>7 (16)</td>
</tr>
<tr>
<td>1 type</td>
<td>79 (40)</td>
<td>8 (18)</td>
</tr>
<tr>
<td>2 types</td>
<td>86 (44)</td>
<td>26 (59)</td>
</tr>
<tr>
<td>3 types</td>
<td>8 (4)</td>
<td>3 (7)</td>
</tr>
<tr>
<td># Physical symptoms</td>
<td>5 (4)</td>
<td>5 (5)</td>
</tr>
</tbody>
</table>

* $p < .05$ ** $p < .01$
Table 2. Indices used to detect the presence of overdispersion and to determine best fit model between standard Poisson, overdispersed Poisson regression, and negative binomial models

<table>
<thead>
<tr>
<th>Step</th>
<th>Scaling factor</th>
<th>Negative binomial $\alpha$</th>
<th>AIC</th>
<th>BIC</th>
<th>AIC</th>
<th>BIC</th>
<th>AIC</th>
<th>BIC</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Standard Poisson</td>
<td>Overdispersed Poisson</td>
<td>Negative binomial</td>
<td>Standard Poisson</td>
<td>Overdispersed Poisson</td>
<td>Negative binomial</td>
</tr>
<tr>
<td>1 (Covariates)</td>
<td>1.13</td>
<td>1.00</td>
<td>432.01</td>
<td>377.37</td>
<td>418.41</td>
<td>452.89</td>
<td>398.25</td>
<td>439.29</td>
</tr>
<tr>
<td>2 (Culture Group)</td>
<td>1.11</td>
<td>1.00</td>
<td>428.15</td>
<td>373.51</td>
<td>415.43</td>
<td>452.52</td>
<td>397.87</td>
<td>439.80</td>
</tr>
<tr>
<td>3 (Commitment to Family)</td>
<td>1.12</td>
<td>1.00</td>
<td>429.52</td>
<td>374.88</td>
<td>416.82</td>
<td>457.36</td>
<td>402.72</td>
<td>444.67</td>
</tr>
<tr>
<td>4 (Culture Group x Commitment to Family)</td>
<td>1.10</td>
<td>1.00</td>
<td>426.46</td>
<td>371.82</td>
<td>415.67</td>
<td>457.79</td>
<td>403.14</td>
<td>447.00</td>
</tr>
</tbody>
</table>

Note: Scaling factor $>1$ or negative binomial $\alpha > 0$ indicates overdispersion

Note: AIC = Akaike Information Criterion; BIC = Bayesian Information Criterion
**Table 3.** Hierarchical Poisson regression predicting the number of stressor appraisals reflecting threats to commitment to family using the overdispersed Poisson regression model

<table>
<thead>
<tr>
<th>Step</th>
<th>Variables</th>
<th>$B$</th>
<th>$SE_B$</th>
<th>$p$</th>
<th>Deviance $(df)$</th>
<th>$\Delta$ Deviance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Covariates</td>
<td></td>
<td></td>
<td></td>
<td>265.10 (234)</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td>Sex (Men=0)</td>
<td>0.56</td>
<td>0.23</td>
<td>.012*</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Education</td>
<td>-0.002</td>
<td>0.03</td>
<td>.940</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td># Treatment modalities (None=0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 type</td>
<td>0.37</td>
<td>0.40</td>
<td>.355</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 types</td>
<td>0.44</td>
<td>0.38</td>
<td>.250</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 types</td>
<td>-0.38</td>
<td>0.83</td>
<td>.647</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Covariates</td>
<td></td>
<td></td>
<td></td>
<td>259.24 (233)</td>
<td>5.86*</td>
</tr>
<tr>
<td></td>
<td>Sex (Men=0)</td>
<td>0.58</td>
<td>0.22</td>
<td>.010*</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Education</td>
<td>-0.002</td>
<td>0.03</td>
<td>.940</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td># Treatment modalities (None=0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 type</td>
<td>0.37</td>
<td>0.40</td>
<td>.355</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 types</td>
<td>0.44</td>
<td>0.38</td>
<td>.250</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 types</td>
<td>-0.38</td>
<td>0.83</td>
<td>.647</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Culture group (Western-born Caucasians=0)</td>
<td>0.57</td>
<td>0.24</td>
<td>.017*</td>
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<td>3</td>
<td>Covariates</td>
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<td></td>
<td></td>
<td>258.61 (232)</td>
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</tr>
<tr>
<td></td>
<td>Sex (Men=0)</td>
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<td>0.22</td>
<td>.011</td>
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<tr>
<td></td>
<td>Education</td>
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<td>0.03</td>
<td>.830</td>
<td></td>
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</tr>
<tr>
<td></td>
<td># Treatment modalities (None=0)</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 type</td>
<td>0.35</td>
<td>0.40</td>
<td>.377</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 types</td>
<td>0.42</td>
<td>0.38</td>
<td>.271</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 types</td>
<td>-0.34</td>
<td>0.83</td>
<td>.686</td>
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<tr>
<td></td>
<td>Culture group (Western-born Caucasians=0)</td>
<td>0.59</td>
<td>0.24</td>
<td>.015*</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Commitment to Family</td>
<td>-0.04</td>
<td>0.06</td>
<td>.447</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Covariates</td>
<td></td>
<td></td>
<td></td>
<td>253.55 (231)</td>
<td>5.06*</td>
</tr>
<tr>
<td>Step</td>
<td>Variables</td>
<td>B</td>
<td>SE B</td>
<td>p</td>
<td>Deviance (df)</td>
<td>Δ Deviance</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>----------------------------------</td>
<td>-----</td>
<td>------</td>
<td>------</td>
<td>---------------</td>
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<tr>
<td>Sex (Men=0)</td>
<td></td>
<td>0.55</td>
<td>0.22</td>
<td>.015</td>
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<td>Education</td>
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<td>0.03</td>
<td>.914</td>
<td></td>
<td></td>
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<tr>
<td># Treatment modalities (None=0)</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>1 type</td>
<td></td>
<td>0.39</td>
<td>0.40</td>
<td>.331</td>
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</tr>
<tr>
<td>2 types</td>
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<td>0.38</td>
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<td>3 types</td>
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<td>0.83</td>
<td>.702</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Culture group (Western-born Caucasians=0)</td>
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<td>-1.38</td>
<td>1.05</td>
<td>.189</td>
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<td></td>
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<tr>
<td>Commitment to Family</td>
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<td>-0.12</td>
<td>0.06</td>
<td>.082</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interaction</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Culture Group x Commitment to Family</td>
<td></td>
<td>0.28</td>
<td>0.14</td>
<td>.045*</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* p < .05
Chapter 7
General Discussion

In this thesis, I conducted a series of studies to investigate the influence that cultural values have on the appraisal of HNC-related stressors. Although each of the studies contains its own discussion section, this chapter highlights issues that relate more generally to cross-cultural psychosocial oncology research.

The original intent of this research was to test whether those who highly endorse VERT-HOR IND and COL will more likely report stressor appraisals that reflect threats to those cultural syndromes than people who do not endorse them as highly. Unfortunately, I discovered that the measure selected to represent cultural syndromes, the ICS, did not tap the intended constructs in adult Western-born Caucasian and Chinese immigrants with HNC (Chapter 4). Thus, I extracted a new, common factor structure that could represent cultural values consistently between the Caucasian and Chinese people with HNC. The new measurement model taps three concepts: Camaraderie with Co-workers, Commitment to Family, and Competitiveness. I verified the fit of the new 3-factor model in the HNC Western-born Caucasian and Chinese immigrant data from which it was derived and evaluated its measurement invariance. The new measurement model initially achieved partial weak invariance, with the equality constraint released for one item, “It is my duty to take care of my family, even when I have to sacrifice what I want.” When the item was removed and the analysis was repeated, the new 7-item, 3-factor model achieved weak invariance, indicating that the factor loadings for the seven items were equivalent across the two HNC groups and the new subscales can be used meaningfully in correlational analyses.

I replicated the HNC findings in previously-collected ICS data from independent samples of Western-born Caucasians and Asian-born Chinese with ESRD or Type 2 DM and English-speakers with RA (Chapter 5). The findings corroborated the HNC results: the original ICS measurement model was disconfirmed and the new 3-factor model was cross-validated at the level of weak invariance in people with various chronic diseases. Based on these findings, I decided to use the new three subscales of Camaraderie with Co-workers, Commitment to Family, and Competitiveness as the measure of cultural values in subsequent analyses to test my hypothesis. Although it deviated from the original plan, this approach engendered greater confidence that the findings would not be biased by measurement error.
I hypothesized when people strongly endorse a cultural value, they are more likely to appraise cancer-related stressors as stressful because they threaten that cultural value. To test this hypothesis, it became necessary to identify a set of stressor appraisals that reflected threats to each of the cultural values of interest (i.e., camaraderie with co-workers, commitment to family, and competitiveness) tapped by the new subscales. Only appraisals reflecting threats to commitment to family (and very few that reflected threats to both camaraderie with co-workers and commitment to family), however, were identified by independent coders when they reviewed qualitative stressor appraisals. This limited the focus of analysis to the Commitment to Family subscale and to stressor appraisals reflecting threats to commitment to family.

Although unforeseen measurement issues necessitated many changes to the original design of this research, ultimately, I was able to test and find support for my original hypothesis: The ways in which people appraised cancer-related stressors is influenced, at least in part, by the cultural values they hold dear.

7.1 “Culture” in the chronically ill context

7.1.1 Measuring culture

Although not a primary objective of this thesis, much effort was spent on verifying the measurement of VERT-HOR IND and COL by ICS in the HNC population. This process was particularly important because the ICS has rarely (if at all) been employed in people with serious disease, including cancer [261]. Thus, its psychometric properties were uncertain.

Due to its complexity, culture is a difficult concept to measure [71]. Researchers have typically employed two alternative strategies to represent it. Some have relied on a person’s country of origin or ethnicity as the explanatory variable to investigate cultural influences on cancer experience (e.g., [67]). Ethnic-group differences in psychosocial constructs are attributed to the assumed cultural syndromes that are believed to differ among groups (e.g., [154]). The country of origin and ethnicity provide unambiguous distinctions between groups and are easy to apply when recruiting research participants. Despite its apparent face validity, however, long-held assumptions about culture and cultural differences have been challenged [119]. For example, when IND is represented as personal uniqueness, Americans are higher in IND than Japanese. This is consistent with widely held beliefs. Yet, the groups do not differ when IND is
characterized in terms of competition [78]. Although one would expect people from Chinese culture to maintain stronger family ties as compared those from Western cultures (e.g., Americans), Oyserman et al. [78] observed that Americans and Chinese people value family relationships and the fulfillment of family obligations to a similar extent. Americans, however, tend to regard fulfilling familial obligations as discretionary (i.e., a matter that can be determined by individual choice), whereas Chinese people tend to think of it as an unconditional duty [78]. These findings underscore the importance of verifying underlying assumptions about ethnic and culture groups, IND-COL, and culturally based values. This approach also assumes that all individuals within a group hold the same cultural syndromes to the same extent [81], but this is unlikely [79]. The strategy of equating culture with place of origin or ethnicity thus risks misinterpreting findings based on erroneous cultural assumptions.

The second strategy commonly employed in cultural research focuses on specific cultural elements (e.g., values and attitudes) that relate systematically to psychological outcomes. Due to the specificity of these cultural elements, as compared to broader cultural syndromes such as IND-COL, they can better predict people’s reactions to cancer [81]. Testing such hypothesized associations can inform the development of culturally sensitive interventions. On the other hand, as is true for many complex phenomena (e.g., illness intrusiveness) [44], many factors and pathways intervene between culture and illness experience. By focusing on specific pathways, we may miss the naturally occurring, synergistic effects that multiple cultural factors may have on outcomes of interest. For example, the extent to which individuals endorse familism may be moderated by their degree of acculturation [262], which in turn affects the importance they place on fulfilling familial obligations while coping with disease.

To further our understanding of culture’s influence on the illness experience, we must rethink how we measure culture. Researchers are encouraged to employ measures that tap relevant cultural dimensions, in addition to country of origin or ethnicity. Cultural values do not fully describe people from the same ethnic group or country of origin [119], nor do all people from the same ethnic group hold the same values to the same extent [79]. Each of these variables taps a different aspect of culture. Hence, incorporating multiple variables to represent complementary facets of culture can provide a more comprehensive explanation of the complex role that culture plays in shaping the cancer experience.
7.1.2 Relevance of individualism-collectivism in psychosocial-oncology research

The original objective of this thesis was to examine the influence of IND and COL on the appraisals of HNC-related stressors. Due to measurement invariance issues with the ICS, I subsequently employed newly derived subscales to measure three cultural values (i.e., camaraderie with co-workers, commitment to family, and competitiveness) to test my hypothesis. Although further testing is required to confirm the construct validity of the three newly derived constructs, they conceptually reflect specific aspects of IND and COL. Camaraderie with co-workers and commitment to family conceptually reflect COL’s emphasis on one’s relationship with others and prioritizing group needs above one’s own, while competitiveness reflects IND’s emphasis on distinguishing oneself from others [79].

Other well-established psychological measures have undergone similar developmental challenges, requiring measurement model refinement. An example is the Minnesota Multiphasic Personality Inventory (MMPI) [263]. The MMPI comprises 10 psychopathology scales that were created using an atheoretical, “empirical keying” technique—items were assigned to subscales based on whether people with given psychopathological diagnoses endorsed them [264]. To improve instrument sensitivity, others proposed interpreting the individual scale scores as a profile of scores, thus diagnosis would be less influenced by idiosyncratic changes in a few subscales [265]. Subsequent experience with the instrument indicated, however, that substantial item overlap across subscales limited the instrument’s ability to discriminate among clinical groups. Further, refinement of the instrument by Tellegen et al. [266] involved the adoption of a theory-based, statistically driven approach to inform scale composition. The MMPI-2 Restructured Clinical (RC) scales were developed using exploratory factor analysis to extract nonoverlapping scales that are distinct from non-specific distress and cohere to a single, clinical concept [266]. Findings support that the MMPI-2 RC improved its convergent and discriminant validity from its predecessor [267]. Though the debate on the psychometric properties of the MMPI-2 RC continues (e.g., [268,269]), this example illustrates that even very widely used instruments undergo continuous refinement, which can involved rescoring existing scales and identifying new ones using factor analysis.

The 16-item ICS does not measure the corresponding cultural syndromes in Caucasians and Chinese immigrants with diverse chronic or life-threatening diseases. Its measurement model is
not adequate to examine the relations among these cultural syndromes and illness-related phenomena. Yet, the psychometric limitations of this instrument do not disconfirm the theoretical framework of IND-COL or its usefulness in psychosocial oncology research; rather, they offer support for Oyserman et al.’s call to identify the “active ingredients” ([78], p. 41) of IND-COL—the most consistent and essential aspects of these cultural syndromes—and include them in efforts to explain cross-cultural differences. Specifically, Oyserman et al. [78] identified “personal independence” as the most common operational definition for IND, whereas they identified “duty to in-group” as the most consistent facet employed to represent COL. Although the revised measurement model I derived did not include a subscale that taps personal independence, the concept of Commitment to Family corresponds closely to “duty to in-group.” Triandis and Gelfand [91] also found that VC is associated with family integrity, defined as a good and lasting relationship between parents and children [89]. Therefore, the Commitment to Family subscale in this thesis can provide more reliable measurement of COL and greater theoretical clarity [78]. Taras et al. [71] also endorse the strategy of defining and operationally defining culture in terms of specific dimensions to reduce the risk of construct contamination.

What does this mean for psychosocial research concerning IND and COL? Triandis [79] identified more than 60 distinct dimensions of IND and COL, including the VERT-HOR dimension. It is unlikely that a single instrument can adequately tap so many components of IND and COL in a reliable and concise fashion [71,82]. Yet, these conceptually broad cultural syndromes can be used as unifying constructs in discussing a wide array of specific IND-COL components and their relations to psychosocial processes and outcomes across different studies in a succinct and meaningful way. Similar conceptual issues have been raised in the coping literature (for review, see [230]). Researchers have theorized and discussed the effects of problem-focus and emotion-focus coping on psychosocial well-being. However, what they measure is often specific examples of problem-focus and emotion-focus coping strategies (e.g., focusing on the next step required to achieve one’s goals and engaging in distracting activities to manage distress, respectively). If clinicians are to be effective in addressing cultural issues in psychosocial oncology, it will be crucial to develop and test theories that describe how IND and COL shape the experience of cancer. Furthermore, we need to identify specific, cancer-relevant cultural values, such as commitment to family, that can influence the perception and experience of cancer stressors. Informed by a broad theoretical framework, it should be possible to develop
concrete clinical interventions and to identify treatment targets by focusing on specific IND-COL elements.

7.1.3 “Culture” in cross-cultural psychosocial oncology research

Cross-cultural psychology research traditionally aims to understand the differences in basic psychological phenomena, such as self-construal and cognition, across people from different countries of origin, of different races or ethnicities (e.g., [85,270]). Yet, limited effort has extend this type of research to understand the experience of living with a serious disease. Most psychosocial-oncology research with an interest in cultural issues tends to focus on differences in the psychosocial impact of cancer among people from different cultural backgrounds (e.g., [271,272]). Investigation into other aspects of culture, beyond group membership, may help identify specific cultural factors under which interventions may produce the most benefits.

For example, Midtgaard et al. [273] examined the impact of group-exercise program participation on the well-being of people undergoing chemotherapy for cancer. The program aimed to offer its participants (a) mutual understanding of the cancer experience and (b) a positive and proactive sense of self as a cancer patient. Investigators hoped the latter would contribute to improved mental health and QOL. The authors reasoned that these outcomes would result when participants experienced of a sense of “group cohesion” (i.e., the tendency for a group to be united in pursuing instrumental goals or satisfying members’ emotional needs; [274]). Future research might investigate whether people who strongly value interdependence experience greater improvement in psychosocial well-being from a group-cohesion-focused intervention, as compared to one that does not emphasize group process, because the intervention fits with their values and priorities.

The extent to which the stress of life-threatening disease alters culturally based values also merits investigation: do these beliefs change in response to the adaptive challenges and coping demands associated with serious disease? If so, are some values more powerfully affected than others? Evidence suggests that this may be the case. Some people experience post-traumatic growth (also known as “benefit-finding”) as a result of their experiences with cancer [275]. People from different cultures such as Chinese and Dutch have reported that experiences with cancer led to positive changes in life priorities, such as increased self-confidence and feeling closer to others (e.g., [276,277]). Significant independent life events, such as migration, can also shape cultural
values. People increasingly endorse a host country’s dominant cultural values as they spend more time living in the new country (e.g., [278,279]). Yet, immigrants do not completely abandon their original values. Rather, they tend to amalgamate both “old” and “new” cultural values and create their own unique culture [280]. This newly amalgamated culture may create different perspectives on cancer-related stressors and events. Studies that have included respondents with varying levels of acculturation revealed different levels of comfort in dealing with health care professionals and beliefs about cancer and its treatment [67,68]. To investigate the stability of cultural values, one might compare culturally based value endorsements between people with serious disease and those in good health or follow people from before to after diagnosis of disease.

Culture is a complex concept, and the challenges in studying it are significant. Yet, it is fundamental to our understanding of the cancer experience. In order to inform clinical practice, we need to look beyond simply identifying specific psychosocial issues in cancer that affect people from different cultural backgrounds. We need to focus on understanding the mechanisms by which culture shapes the cancer experience, and refine its measurement to better capture variations that may result from transitioning between different stages of the cancer journey (e.g., from diagnosis to survivorship).

7.2 Identification of cancer appraisals

The third study in this thesis examined the association between cultural values and cancer appraisals. To generate data on cancer appraisals, I employed the CRSC [41] to provide a list of common HNC-related stressors. The CRSC asks respondents to indicate whether an event has occurred, a commonly used format [281]. Empirical knowledge about physical and psychosocial issues experienced by those with HNC is often based on data gathered by checklists. An advantage of using checklists to document stressor exposures is that they can be used to estimate the prevalence of various outcomes within a population of interest. For example, fatigue (78%) and anxiety (77%) were the most common cancer-related concerns reported by a mixed-diagnosis sample of Canadians with cancer \(n = 899\) [42]. This information can inform: (a) strategies about the problems most urgently in need of intervention and (b) about how intervention efforts might be prioritized to achieve the most benefit for the largest numbers of people with the condition. A disadvantage of checklists, however, is that they do not provide
information about the underlying mechanisms by which the events cause stress. Checklists offer information about whether or not a stressor has occurred, but the interpretation of what constitutes the “occurrence” of a stressor may vary widely from one person to another [117]. One study indicated, for example, that the most common symptoms reported by 128 Hong Kong Chinese with nasopharyngeal cancer were dry mouth (97%), choking (85%), and swallowing difficulties (85%) [64]. When a subsample of 60 respondents was interviewed in-depth, however, their qualitative responses indicated that respondents under-reported the frequency of swallowing difficulties because they did not interpret every instance of dysphagia as a “difficulty.” Hence, it is essential to understand personal interpretations of HNC-related stressors in order to establish meaningful treatment targets. Discussions about the use of checklists in relation to coping have highlighted similar measurement challenges [282, 283]. When collecting stressor prevalence data via checklists, it is important to augment this with other complementary sources of data to gauge people’s subjective experience. One way to achieve this is to incorporate questions about the respondent’s perceptions of the stressors in the checklist.

As part of the process to generate a taxonomy of stressor appraisals, I asked respondents to identify the reasons for which they found each of the CRSC stressors to be stressful. I used an open-ended question format. I termed each reported cause of stress a “stressor appraisal”—a statement that provides a single, distinct, and unambiguous explanation about why a respondent experienced stress in a particular cancer-related situation. Stressor appraisals reflect respondents’ interpretations of their experience of the corresponding cancer-related stressors. The definition I used for “stressor appraisal” is different, although not mutually exclusive, from the one Lazarus and Folkman [139] proposed. The latter is a cognitive process in which people determine: (a) whether an encounter has personal significance (i.e., is it benign-positive, irrelevant, or stressful for me?) and (b) whether they have access to sufficient resources to cope effectively with the encounter if it is deemed stressful. The difference between the definition proposed by Lazarus and Folkman and the one employed in this research lies in the level of abstraction; that is, the stressor appraisals in this thesis are perceptions of cancer stressors grounded in the data, whereas Lazarus and Folkman’s appraisals are theoretical categorizations of specific perceptions of stressors. For example, a cause of stress respondents reported when faced with the stressor, “I realize that I may die,” was that they did not want to be separated from their loved ones. I conceptualized this stressor appraisal as “anticipating loss of valued relationships after death.”
Based on Lazarus and Folkman’s theoretical framework, this stressor appraisal would be categorized as a “threat appraisal” because the stressor appraisal reflects an anticipatory loss. By first extracting these context-based stressor appraisals, I was able to categorize them independently of a particular theoretical framework; in the case of this thesis, I chose to categorize the stressor appraisals according to the three cultural values (i.e., camaraderie with co-workers, commitment to family, and competitiveness) measured by the revised ICS subscales. Had I employed an existing measure of primary appraisal (e.g., Cognitive Appraisal of Health Scale [148]; see Section 1.3.1), I would not have been able to determine how these primary appraisals relate to the cultural values of interest. The identification of stressor appraisals offers a glimpse into the diverse ways in which people experienced common cancer situations.

The research team and I identified 184 stressor appraisals that respondents reported in relation to 24 common HNC-related stressors. I anticipated diversity in the ways in which people with HNC perceive the stressors, yet the extent of this variation was beyond my expectation. The wide array of stressor appraisals may be attributed to the large number of stressors, as well as the open-ended question format, employed to capture stressor appraisals. Because the stressor appraisals were generated based on participant responses, rather than a priori established categories, the data provided a more naturalistic depiction of how people with HNC appraise various stressors. An alternative explanation for this large pool of stressor appraisals may be related to the nature of the cancer experience, which comprises many stressful situations that affect multiple aspects of life [31]. A recent examination of the burden of stress in HNC, for example, indicated that people experience a wide range of psychosocial stressors [41]. If I have focused on asking about respondents’ appraisals of HNC in general, it would not have been possible to identify the specific appraisals associated with particular aspects of HNC. This information may help clinicians to address the specific circumstances under which people with cancer encounter cancer-related stress [5].

7.3 Cultural values and cancer appraisals

In the third study, I tested the hypothesis that people’s appraisals of cancer stressors reflect threats to their cultural values; that is, that cancer events are deemed stressful because they make it more difficult for people to adhere to their dominant cultural values. A total of 184 stressor appraisals was extracted from qualitative interview data concerning 24 common cancer-related
stressors. Independent coders categorized the stressor appraisals and interview excerpts to reflect whether they represented threats to one of the three cultural values that were the focus of this study: camaraderie with co-workers, commitment to family, and competitiveness.

7.3.1 Value-irrelevant and -threatening stressor appraisals

The majority of stressor appraisals and interview excerpts were classified as “value-irrelevant;” that is, they did not reflect any threat to the three cultural values under consideration. In fact, many of the stressor appraisals reflected physical and psychological consequences of cancer, such as “side effects” or “threat of death.” These seem to be universal causes of stress, regardless of the stressors or people’s cultural background (e.g., [34,42,67,68,210]).

Many stressor appraisals reflect threats to commitment to family, which included how HNC affects respondents’ loved ones (e.g., “disclosure of diagnosis to loved ones”) or the respondents’ abilities to care for their families (e.g., “threat of [being] unable to care for loved ones if one dies”). The impact of cancer extends beyond the individual; it creates tremendous disruptions to family life and impacts family well-being. Children with a parent diagnosed with cancer often experience adjustment difficulties. These include anxiety and depression in adolescents, as well as behavioural problems and inhibition of cognitive and physical functioning in school-aged children (for review, see [284]). Cancer also interferes with the ability to fulfill family obligations. Parents with cancer struggle to balance the need to fulfill parental obligations and to cope with their own needs [204,285]. They are concerned about how best to disclose the situation to their children to minimize its psychosocial consequences [286]. Because cancer has powerful implications for family well-being and the ability to fulfill familial obligations, commitment to family may be an especially important cultural value for clinicians to consider. This cultural value can inform clinicians about the importance that family concerns may have in shaping people’s perceptions of cancer-related stressors and their psychosocial impact.

We did not identify any interview excerpts that reflected threats to camaraderie with co-workers or competitiveness. The few excerpts that were coded under both commitment to family and camaraderie with co-workers reflected concerns for the well-being of others, collectively. Because they included an ambiguous target (e.g., “others” or “people”), respondents may have been referring to family members and/or work colleagues in these instances. As a result, the coders tended to assign these excerpts to both categories.
The limited number (or lack) of stressor appraisals and interview excerpts reflecting threats to camaraderie with co-workers or competitiveness may indicate that neither value is especially relevant to these respondents’ cancer experience. The literature on cancer and work has primarily focused on the ability to resume work and the financial impact as a result of work-hour reduction or loss of employment [47] (for reviews, see [45,287,288]). Little is known about the effects on collegial relationships when a co-worker has cancer. Some people do not want to disclose a cancer diagnosis to co-workers due to concerns about privacy or fears of negative reactions from others [288]. People may prefer to limit the extent to which work relationships and personal life intersect. Consequently, camaraderie with co-workers may not be a relevant cultural value as a determinant of cancer-related stresses, except under atypical circumstances.

No systematic research has examined the relations between competitiveness and cancer stressor appraisals or their psychosocial impact. Thus, it is unclear whether competitiveness is relevant to the experience of cancer-related stressors. Some survey studies concerning professional/career ambitions in cancer survivors have reported that people who return to work following diagnosis become less ambitious than they were before the onset of cancer [233,289,290], but a small proportion of cancer survivors express increased ambitions in professional and educational domains following diagnosis [289]. Reduced vocational ambition may be explained, in part, by cancer-related limitations to physical and role functioning, and in part, by reprioritizing family life and the enjoyment of life following cancer diagnosis [289]. Being competitive and distinguishing oneself from others may be less important to people following a cancer diagnosis than at other times and this, in turn, may explain why coders did not detect threats to competitiveness.

Other possible explanations for the lack of stressor appraisals related to camaraderie with co-workers or competitiveness include: (a) none of the stressors directly tapped work-related situations or (b) many of the respondents were not working for pay at the time they completed the research materials. Hence, there were fewer opportunities to reflect on these types of stressors or to identify relevant stressor appraisals.

This thesis focused on categorizing stressor appraisals and interview excerpts into categories that reflect threats to camaraderie with co-workers, commitment to family, and competitiveness. However, this does not preclude the possibility that these stressor appraisals and interview
excerpts may reflect threats to other cultural values. For instance, people from Western cultures tend to value proactive participation in treatment decision-making, whereas those from Eastern cultures tend to respect the authority of health care professionals and to rely on their expertise (e.g., [67]). Researchers interested in medical decision-making preferences may categorize stressor appraisals based on whether they reflect threats to proactive participation (e.g., “difficulty understanding medical information”) or threats to accepting professional recommendations (e.g., “doubts about recommended treatment.”) in this domain.

7.3.2 Moving towards the use of specific cultural values in cultural research concerning psychosocial outcomes

Despite challenges in the measurement of cultural values and identification of value-threatening appraisals, I found support for the hypothesis that people with HNC find cancer-related stressors to be stressful when they threaten dominant cultural values. Specifically, Chinese immigrants who strongly endorsed the value of commitment to family reported more appraisals reflecting threats to commitment to family than those who endorsed this value to a lesser extent. This association was not evident among Western-born Caucasians. Thus, commitment to family does not provide a complete explanation of the relation between culture and the process of stressor appraisal.

Other cultural values likely shape cancer stressor appraisals. For example, self-reliance is highly valued in many cultures. It is relevant in cancer because the disease often impinges on fundamental abilities, such as carrying out activities of daily living (e.g., [30]). Indeed, many of the stressor appraisals (e.g., “loss of independence”) identified in this thesis indicated challenges to the sense of self-reliance. Self-reliance relates to IND, but its meaning varies across cultures. In an individualist context, self-reliance reflects the freedom to do whatever one wishes, whereas in collectivist context, the emphasis is on not being a burden on one’s in-group [89]. Hence, cancer-related stressors may exert deleterious psychosocial effects when they threaten the sense of self-reliance, but culturally specific meanings of self-reliance likely moderate the form of reported appraisals (e.g., reduced personal freedom versus being a burden on others).

There is growing interest in investigating more nuanced cross-cultural influences as they relate to common psychological concepts. For example, a recent meta-analysis examined the moderating effect of IND-COL (as a country-level variable) on locus of control, depression, and anxiety
The authors theorized that people from individualist countries tend to value the pursuit of personal goals and attribute behaviour to personal characteristics. This, in turn, contributes to a greater sense of increased personal control over the environment (i.e., internal locus of control). People from collectivist countries, on the other hand, tend to value connectedness and furthering group priorities; they are more likely to incorporate contextual factors when attributing causation than do people from individualist countries. As a result, people from collectivist countries are more accepting of environmental causes (i.e., external locus of control) than those from individualist ones and are more willing to relinquish personal control for the sake of collective goals. Moreover, undesirable events that are outside of one’s control (i.e., external locus of control) can result in uncertainty, which is characterized by anxiety. The meta-analysis indicated that the association between external locus of control and anxiety was weaker in collectivistic countries than in individualist countries. The authors speculated that this finding may be attributed to the fact that the emphasis is on calmness and harmony in collectivist countries, rather than on personal-goal pursuit and, as a result, may have exerted a muting effect on the observed relation between external locus of control and anxiety.

In a series of studies, Ma-Kellams and Blascovich asked undergraduate students to think about one’s own death. They found that East Asian undergraduate students were more likely to reflect on life and become more motivated to enjoy life. Their European-American counterparts, on the other hand, were more likely to ruminate about death. The authors attributed this difference to the holistic versus analytic worldviews of Eastern and Western cultures, respectively. The holistic worldview allows the coexistence of contradictory information. Thus, thoughts about death likely also trigger thoughts about life because they are intricately linked.

These studies signal a growing appreciation for the more precise influence of specific cultural values (e.g., commitment to family and locus of control) as compared to more global constructs (e.g., IND-COL) in shaping the meaning and impact of events on psychological outcomes. In addition to my thesis findings, mounting empirical evidence supports the hypothesis that culture shapes how we see the world, which in turn, determines our experiences. Research on culture and appraisal can shed light on how and why the experience of cancer-related events varies across people exposed to similar objective events. Understanding cultural determinants of illness experience is especially pertinent in the oncology setting since there is tremendous cultural
diversity in the cancer population, and the disease exerts significant personal and societal impact. Interventions that appropriately reflect cultural perspectives can help to foster patient-centered care.

7.4 Study limitations

Some overall study limitations must be acknowledged. First, the study only recruited Western-born Caucasians and Chinese immigrants with HNC to examine cultural values and the appraisal of cancer stressors. Other groups may (a) vary in the extent to which they maintain the values under consideration in this research (i.e., camaraderie with co-workers, commitment to family, and competitiveness) and/or (b) appraise the same HNC-related stressors as exerting deleterious psychosocial effects for reasons other than those identified in the present sample. As a result, the present dataset may not have captured the full range of cultural values or stressor appraisals. We focused the current investigation on the association between cultural values and stressor appraisals in people with HNC. The findings require replication in other contexts to establish the limits on their generalizability.

Second, this research focused on a very specific way that cancer stressors affect people (i.e., whether they threaten the sense of commitment to family). Yet, cancer stressors can stressful for many reasons (e.g., existential concerns). Because I set out to examine the ways in which stressor appraisals relate to cultural values as measured by the revised ICS, it was not possible to investigate other cancer-stressor appraisals.

Third, instead of posing specific questions to identify value-threatening stressor appraisals, I employed an open-ended question to capture respondents’ stressor appraisals. This was necessary because little was known about the types of stressor appraisals that people with HNC may identify in the context of these specific cancer stressors. The strategy may also have led, however, in the detection of a comparatively small number of value-threatening appraisals, limiting opportunities to test the hypothesized relations in each of the eight CRSC stressor categories. Because the open-ended question approach captured a more naturalistic indication of how cancer stressors are perceived and experienced, the study findings offer a more spontaneous indication of the ways in which culturally based values relate to the appraisal of cancer-related stressors.
Finally, I focused on three specific cultural values as the main determinants to examine cultural variations in stressor appraisals, but other aspects of culture (e.g., meaning of disease and symptoms) may play more prominent roles. It would be important to examine other cultural elements and determine how they shape the appraisal of cancer-related stressors.
Chapter 8
Conclusions

Culture is a complex construct. It is a challenge to understand and study. Notwithstanding, it is fundamental to the cancer experience and thus requires careful measurement and research. As clinicians and researchers, we must expand the ways in which we understand culture by looking beyond group membership and conceptualizing it as a complex social-determinant that shapes cognition, affect, motivation, and behavior. This shift can enable us to achieve new insights about how people perceive cancer and its treatments and how these, in turn, influence psychosocial well-being. Such insights are fundamental to efforts to facilitate adaptation and to provide culturally sensitive, patient-centered care.
9.1 Research and clinical implications

We live in an ever-diversifying, multicultural society; clinicians often encounter patients who hold beliefs and values that differ from their own. Throughout the diagnosis and treatment process, health care providers may inadvertently impose their own culturally based values and beliefs onto their patients, who may not share them [8,293]. This can lead to negative experiences [294] and can hinder treatment progress [295,296]. The impact may be even greater in cancer because the condition is life-threatening nature and requires a high frequency of interaction with health care providers. Because cultural values and beliefs shape perceptions and the experience of disease [297], a better understanding of the relation between cultural values and appraisals promises to elucidate aspects of the illness experience with which clinicians may not be familiar. Clinical and research efforts must attempt to delineate the effects of culture as it shapes the psychosocial impact of cancer and incorporate culturally sensitive approaches in developing new interventions.

Research must validate the conceptualization and measurement of culturally based values in the context of cancer and other diseases. Fundamental questions about the effects of a cancer diagnosis on cultural values and the influence values exert on illness experience remain to be addressed comprehensively. Qualitative interviews might be used to investigate whether fundamental values differ systematically between healthy and ill people. This will determine whether the experience of life-threatening disease leads to changes in basic values. When possible, it would be invaluable to measure cultural values before and after people receive a diagnosis to address this question. We also must ensure that the instruments selected to measure cultural values are factorially invariant across groups to rule out the effects of measurement error. Although it might be desirable, it may not be possible to develop a “universal” measure for specific cultural values due to extensive variations in the conceptualization and manifestation of these values between groups. Should this, in fact, prove to be the case, it will be important to examine cultural values in-context (i.e., within cultures that are homogeneous with regard to the values in question) and to develop psychometrically sound culture-specific instruments. This strategy may allow scholars to understand the cancer experience within cultural perspectives and
may eventually enable identification of common dimensions that underlie specific, culture-group differences.

In terms of clinical implications, these findings are consistent with the position that cultural values help to explain why cancer-related stressors are stressful for those with HNC. To foster culturally sensitive, patient-centered care, clinicians should engage patients in identifying the aspects of life they deem most important and the ways in which they have been affected by cancer and its treatment. Clinicians should inquire about the impact of cancer stressors on important aspects of life. This may encourage people to report concerns, especially among those from cultures that tend to refrain from raising questions when meeting with physicians [8]. Advice should be tailored to address the needs patients identify as most pressing (e.g., how to discuss with loved ones the likely effects of impending disease and treatment on the patient and on others in the family).

9.2 Next steps

In my future work, I plan to explore a phenomenon that I identified from this thesis research: the sense of burden on others. While identifying stressor appraisals in interview transcripts, I observed that the most commonly reported stressor appraisal was “emotional burden on family and friends.” Together with other stressor appraisals such as “unable to contribute” and “feeling useless,” this appears to reflect a broader phenomenon that one may begin to develop a sense of being a burden on others—i.e., the recognition that one cannot fulfill responsibilities associated with his/her social roles, which in turn, may impose additional demands on significant others. This phenomenon has been reported in people with chronic, life-threatening conditions, such as cancer [31,65,298-305]. Its prevalence estimates range from 25% to 77% [31,306-308]. Many find it distressing [31,307]. However, studies to date and the measures they employ focus either on: (a) documenting occurrence (e.g., “the most prevalent social concern was the feeling of being a burden to others” [31], p.243) [31,65,302,309] or (b) estimating the extent to which respondents perceive themselves as burdensome to others [298,303,310-313]. Much of the current literature on the sense of burden on others has not been grounded in a conceptual framework [299]. As a result, the interpretation of sBO and the reasons for which it arises remain ambiguous. To address this gap, I plan to characterize this relatively understudied, clinically relevant phenomenon and begin to build a theoretical understanding of it.
Moreover, the ways in which culture and gender roles may operate to shape the sense of burden on others have not been explored. The sense of burden on others appears to be pan-cultural. It has been reported as a stressor by Asians and Westerners with chronic diseases [312,314-316]. Definitions of “burden” may differ, however, due to fundamental differences in norms and expectations of interpersonal relationships [317]. For example, explicit requests for social support and open discussions of problems are normative and associated with improved psychosocial well-being in Western, individualist cultures, where people are expected to express and satisfy their needs [256]. In contrast, those from East- and South-Asian collectivist cultures tend to fare better when implicitly relying on the social support they expect significant others to provide. Explicit support requests in the latter groups are perceived as burdensome and may strain relationships, leading to poorer outcomes [256,318,319]. Another cultural element is reciprocity, which is an important aspect of family-centered values (e.g., filial piety, familism) in many cultures [320]. The inability to return the help and support one receives from others may be especially distressing when people originate in cultures that emphasize family-related values. The sense of burden on others is also intimately related to social ties and roles. Thus, we expect women and men to differ in the ways in which the phenomenon is expressed. A wealth of research documents profound differences in gender and gender-roles [321]. Women affected by cancer report more role problems than men, regardless of whether they are patient or caregiver [322]. Women are more likely than men to prioritize family roles over work roles [260]. As compared to men, women are more sensitive to and distressed by the negative life events that affect others they love [202,203]. Thus, by examining the sense of burden on others within the context of culture and gender, it will further inform how people with cancer come to experience this phenomenon.

Although this phenomenon has been observed clinically, we do not yet know how clinicians come to recognize this sense of burden on others as a stressor in cancer. Social workers are often the primary providers of psychosocial services in oncology treatment-centers and community health-care settings throughout the world [323], in part, because of the versatility of their practice [324]. They are thus, well positioned to detect and address this problem when it arises. By comparing social workers’ clinical observations against patients’ experiences of the sense of burden on others, it may be possible to begin evaluating how effectively such concerns are currently recognized and addressed. Discrepancies may indicate a service gap.
In a multi-stage study, I aim to: (a) explore the meaning of the sense of burden on others by interviewing men and women with HNC who are English-speaking Canadians from diverse cultural backgrounds, with specific emphasis on recruiting Chinese and South-Asian immigrants (the two most populous non-English-mother-tongue immigrant groups in Toronto, Canada [325]), and (b) identify social workers’ current knowledge and practices in detecting and addressing the sense of burden on others by conducting focus groups. Thematic analysis of the interview and focus-group transcripts using the qualitative descriptive approach, as described by Sandelowski [326] can identify important, implicit themes and contrast how the sense of burden on others is characterized by both people with HNC and practicing social workers, as well as between culture groups and between men and women. I expect that the findings will: (a) address an under-studied psychosocial phenomenon that affects people with HNC; (b) reveal whether culture and gender play a role in shaping how people with HNC experience and express the sense of burden on others; and (c) determine whether there are discrepancies between the personal meaning of the sense of burden on others expressed by people with HNC and social workers’ clinical observations of the phenomenon.
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Appendices
Appendix A
Demographics form
In selecting the circle, please shade like this: ●
If you accidentally mark the wrong answer, please place a large X on the incorrect one like this: ●

Date of Birth
(dd) (mm) (yyyy)

Sex
○ Male
○ Female

Age

Medical Record Number (Blue Card)

First Name

Initial Last Name

Address: No. and Street

City

Apt. No.

Postal Code

Phone No.

1. What is your marital status?
○ a. Never married  ○ b. Married or common-law ○ c. Separated  ○ d. Widowed  ○ e. Divorced

2. How many children do you have?
○ a. none  ○ b. 1  ○ c. 2  ○ d. 3  ○ e. 4  ○ f. 5  ○ g. 6 or more

3. Friends and Relatives:
   a) How many close friends do you have? (People that you feel at ease with, can talk to about private matters, and can call on for help).
   ○ none  ○ 1 or 2  ○ 3 to 5  ○ 6 to 9  ○ 10 or more
   b) How many relatives do you have that you feel close to?
   ○ none  ○ 1 or 2  ○ 3 to 5  ○ 6 to 9  ○ 10 or more
   c) How many of these friends or relatives do you see at least once a month?
   ○ none  ○ 1 or 2  ○ 3 to 5  ○ 6 to 9  ○ 10 or more

4. Church and Group membership: Do you belong to any of these kinds of groups?
   a) a social or recreational group? □ Yes □ No
   b) a labour union, commercial group, or professional organization? □ Yes □ No
   c) a church group? □ Yes □ No
   d) a group concerned with children (PTA, Boy Scouts, etc.)? □ Yes □ No
   e) a group concerned with community betterment, charity or service? □ Yes □ No
   f) any other group? □ Yes □ No
   Describe below:

Study 3 - English V1new 03/22/2006
5. What is your present occupation?
- a. Full-time paid employment (30 hrs or more/week)
- b. Part-time paid employment (< 30 hrs/week)
- c. Self-employed
- d. Unemployed
- e. Homemaker
- f. Student
- g. Retired
- h. Long-term disability or sick leave

6. How far did you go in school?
- a. No Formal Education
- b. Primary school (some or completed)
- c. Secondary school (some or completed)
- d. Post-secondary (some or completed) e.g. college, technical school
- e. University (Bachelor level)
- f. Graduate or Professional School

7. Total number of years in school?
   (Beginning at Grade 1) 
   Years

8. What is your annual household income?
- a. Less than $25,000
- b. $25,000 - $49,999
- c. $50,000 - $74,999
- d. $75,000 - $99,999
- e. $100,000 - $149,999
- f. $150,000 or over

9. PLACE OF BIRTH
- a. Born in North America (Canada or USA)
- b. Born in Asia  Country of Birth - Specify

Study 3 - English V1new  03/22/2006
10. ETHNIC BACKGROUND

a) If born in Canada:

Were your parents, grandparents or great-grandparents born outside of Canada? Most recent:
- a. Parent
- b. Grandparent
- c. Great-grandparent

Country - Specify

b) If born outside Canada:

How old were you when you came to Canada?
- a. Preschooler (Age 0-3)
- b. Young Child (Age 4-12)
- c. Teenager (Age 13-17)
- d. Adult (Age 18 or above)

Year of Immigration

11. What is your first language (or mother tongue)?
- a. English
- b. Cantonese
- c. Mandarin
- d. Other Specify

12. What other languages do you know well enough to speak and make yourself understood?
- a. None
- b. English
- c. Mandarin
- d. Cantonese
- e. Other Specify

13. What is your religion?
- a. None
- b. Buddhism
- c. Protestant
- d. Catholic
- e. Jewish
- f. Islam
- g. Other Specify
請在你的答案旁塗滿圓圈：●
如你意外地塗錯了，請如右圖所示畫上交叉●

第一部份 ○ 採訪員填寫

出生日期：日 月 年

性別 ○ 男 ○ 女

醫院登記號碼（醫院藍卡）

受訪者名字（英文） 受訪者姓氏（英文）

住址號碼及街道名稱 單位號碼

城市 郵區號碼 電話號碼

1. 你的婚姻狀況：
   ○ a. 從未結婚 ○ b. 已婚或同居 ○ c. 分居 ○ d. 喪偶 ○ e. 離婚

2. 你有多少名兒女？
   ○ a. 0 ○ b. 1 ○ c. 2 ○ d. 3 ○ e. 4 ○ f. 5 ○ g. 6 或以上

3. 親友：
   a) 你有多少個親密朋友（一些你感到能容易相處，可以談及私事，及可以致電求助的）？
   ○ 沒有 ○ 1-2 ○ 3-5 ○ 6-9 ○ 10 個或以上
   b) 你有多少個你覺得比較親密的親戚（父母、兄弟姊妹、夫/妻及子女以外）？
   ○ 沒有 ○ 1-2 ○ 3-5 ○ 6-9 ○ 10 個或以上
   c) 這些親密朋友或親戚之中，有多少個你會最少一個月見一次面？
   ○ 沒有 ○ 1-2 ○ 3-5 ○ 6-9 ○ 10 個或以上

Chinese questionnaire version 1 dated November 30, 2005
10. 族裔背景:
   a) 如在加拿大出生:
      你的父母、祖父母或曾祖父母中有哪一位在加拿大以外出生？
      ○ a. 父母 ○ b. 祖父母 ○ c. 曾祖父母
      國家－詳述

   b) 如在加拿大以外出生:
      你剛來到加拿大的時候是幾歲？
      ○ a. 0 - 3歲 ○ b. 4 - 12歲 ○ c. 13 - 17歲 ○ d. 18歲或以上
      移民年份

11. 你的母語:
   ○ a. 英語 ○ b. 廣東話 ○ c. 普通話 ○ d. 其他，請詳述

12. 你還能流利地說其他哪種語言？
   ○ a. 無 ○ b. 英語 ○ c. 普通話 ○ d. 廣東話 ○ e. 其他，請詳述

13. 你有沒有宗教信仰?
   ○ a. 沒有 ○ d. 天主教 ○ g. 其他，請詳述
   ○ b. 佛教 ○ e. 猶太教
   ○ c. 基督教 ○ f. 伊斯蘭教
Appendix B

Consent forms
**Risks:** Should you choose to participate in this study, you will be asked to complete standard questionnaires about how you cope with your illness in a confidential interview format. There is very little risk associated with this study. It is possible, however, that you may find it upsetting to talk about these issues. We can help you to meet with a qualified professional if you are interested.

**Benefits:** There is no medical benefit from your participation in this study. We hope that information learned from this study will help cancer patients in the future.

**Participation:** Your participation in this study is voluntary. Should you agree to participate, you are free to omit any items from the interview that you prefer not to answer or to withdraw from the study at any time without jeopardizing your health care. You are free to refuse the tape recording of your interview. You will receive the same high quality medical care regardless of whether you participate in this study.

**Confidentiality:** All personal information including the audio tapes will be held in strict confidence. You will be identified by a study number only. No names or identifying information will be used in any publication or presentations. No information identifying you will be transferred beyond the research team or this hospital. If any information relevant to your care should become evident during your participation in this study, we will, with your permission, assist you in bringing this to the attention of your cancer doctor.

**Reimbursement:** We will provide you with $20 for participation in this study.

**Questions:** If you have any general questions about the study, please call the Principal Investigator of this study, Dr. Gerald Devins at 416-340-3113, or the study coordinator, Mrs. Colleen Simpson at 416-340-4800 ext. 3093. If you have any questions about your rights as a research participant, please call Dr. R. Heslegrave, Chair of the University Health Network Research Ethics Board at (416) 340-4557. Dr. Heslegrave is not involved with the research project in any way and calling him will not affect your participation in the study.

**Consent:** I have had the opportunity to discuss this study and my questions have been answered to my satisfaction. I consent to take part in the study with the understanding I may withdraw at any time without affecting my medical care. I have received a signed copy of this consent form. I voluntarily consent to participate in this study and I voluntarily consent to allow the research team to obtain needed information from my doctor and hospital chart.

<table>
<thead>
<tr>
<th>Participant’s Name (Please Print)</th>
<th>Participant’s Signature</th>
<th>Date</th>
</tr>
</thead>
</table>

I confirm that I have explained the nature and purpose of the study to the participant named above. I have answered all questions.

<table>
<thead>
<tr>
<th>Name of Person Obtaining Consent</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>
同意書

文化症狀及癌病對生活侵擾的處理

首席研究員： Dr. Gerald M. Devins (戴偉誠博士)

研究小組成員： Dr. Lillian Siu Dr. Johnathan Irish Dr. Ruth Lee (李潔凱博士)
Dr. Gary Rodin Dr. Kenneth Mah Dr. Sophie Lebel
Ms. Ada Wong Ms. Ka Ming Fong (方嘉明女士)
Ms. Melissa Oliver Ms. Vivian Tsung (宗德緯女士)

聯絡電話： 416-340-4800，內線 3093 (多倫多全科醫院)

研究經費贊助： 加拿大健康研究協會

序言： 你現正被邀請參與一項研究。在你答允參與前，閱讀及了解以下有關此
項研究程序的解釋是非常重要的。以下的資料簡介了研究的目的、程序、參與研究的利
弊、可能引起的不安及需特別注意的地方等。這些資料亦提到你可隨時終止或拒絕參予此
項研究的權利。在決定是否參與此項研究前，你應充份了解有關的利弊以便作出知情的抉
擇。這就是知情同意程序。在簽署同意書前，請向有關研究人員要求解釋任何你不明白的
字句。請確保你所有的疑問都得到滿意的解答，才簽署此份同意書。

研究目的： 此項研究的長遠目標是為解決不同背景的人如何處理癌症及其治療所帶
來的各種影響，及研究用不同處理方法的人，如何學習在困難中活得健康。我們的研究仔
細探討年齡在 18 歲至 80 歲之間 ( 甚至更年長者 ) 的男女的處理方法。除此以外，我們
題，請聯絡我們醫院的研究道德委員會主席，赫憲紀博士（Dr. R. Heslegrave），電話：416-340-4557。赫博士並沒有牽涉於這個研究項目中，故此聯絡他並不會影響你的參與。

表示同意：本人有機會與研究人員討論此項研究，同時我的問題亦得到滿意的解答。本人同意參與這項研究，亦明白到我可隨時退出而不影響我的醫療服務。本人已取得一份已簽署的同意書副本。本人自願同意參與此項研究，並自願允許研究人員從我的醫生及入院病歷取得所需的資料。

_________________________   ________________________  日期：二零零__年__月__日
參加者姓名                參加者簽名

我確定已向上述參加者解釋此項研究的性質及目的，並且已回答所有的問題。

_________________________   ________________________  日期：二零零__年__月__日
獲取同意者姓名                獲取同意者簽名
同意研究人員聯絡
有關將來的研究項目

文化症狀及癌病對生活侵擾的處理的研究

本人同意此項研究小組的其中一位成員於將來聯絡我，並徵詢我是否有興趣參加跟進此項研究的一些研究項目。

_________________________  ________________________  日期：二零零__年__月__日
參加者姓名  參加者簽名

參加者的電話號碼：________________________

可聯絡參加者的人：________________________  電話號碼：________________________
姓名
Appendix C
Refusal forms
Refusal Form

Cultural Syndromes, Coping, and Illness Intrusiveness in Cancer

I do not want to participate in the study
○ a. and do not agree to allow the researchers to use any information about me.
○ b. but I agree to allow the researchers to use information about my age, sex, race and the "T-stage" of my cancer to evaluate the representativeness of the results.

First Name ___________________________ Initial _______ Last Name ___________________________

Signature ___________________________

1. Age (year) ________________________
   ○ a. Male
   ○ b. Female

2. Sex _______________________________
   ○ a. Male
   ○ b. Female

3. Race _______________________________
   ○ a. Caucasian
   ○ b. Chinese

4. UICC AJCC stage grouping
   ○ a. Stage 0
   ○ b. Stage IA
   ○ c. Stage IB
   ○ d. Stage IIA
   ○ e. Stage IIIB
   ○ f. Stage IIIA

   ○ g. Stage IIIB
   ○ h. Stage IIIC
   ○ i. Stage IVA
   ○ j. Stage IVB
   ○ k. Stage IVC
   ○ l. Stage V

I agree to have a member of the research team contact me to ask whether I might be interested in participating in future follow-up studies.

Signature ___________________________ Print Name ___________________________

Refusal Background Information Study 3 dated January 27, 2005
文化症狀及癌病對生活侵擾的處理

本人不欲參予此研究

○ a. 亦不允許研究人員採用任何有關本人之資料。
○ b. 但本人允許研究人員採用本人之年齡、性別、種族資料及本人癌症 “腫瘤期”
以作評估結果的代表性。

受訪者姓名

受訪者姓氏

簽名

2. 性別
○ a. 男
○ b. 女

3. 種族
○ a. 白人
○ b. 華人

4. UICC/AJCC 癌症階段組織
○ a. 0 期
○ b. IA 期
○ c. IB 期
○ d. IIA 期
○ e. IIB 期
○ f. IIA 期
○ g. IIIB 期
○ h. IIIC 期
○ i. IVA 期
○ j. IVB 期
○ k. IVC 期
○ l. V 期

5. 本人同意此项研究小組的其中一位成員於將來聯絡我，並徵詢我是否有興趣參加跟進此项研究的一些研究項目。

簽名

Chinese Refusal Background Information Version 1 dated January 23, 2005
Appendix D

Individualism-Collectivism Scale (ICS)
Please select one number from the entire scale that best represents how much you agree or disagree with each statement.

1. My happiness depends very much on the happiness of those around me.
   Disagree 1 2 3 4 5 6 7 8 9
   Very Much
   Agree

2. Winning is everything.
   Disagree 1 2 3 4 5 6 7 8 9
   Very Much
   Agree

3. I usually sacrifice my self-interest for the benefit of my group.
   Disagree 1 2 3 4 5 6 7 8 9
   Very Much
   Agree

4. It bothers me when other people perform better than I do.
   Disagree 1 2 3 4 5 6 7 8 9
   Very Much
   Agree

5. It is important for me to maintain harmony within my group.
   Disagree 1 2 3 4 5 6 7 8 9
   Very Much
   Agree

6. It is important to me that I perform my job better than others.
   Disagree 1 2 3 4 5 6 7 8 9
   Very Much
   Agree

7. I like sharing little things with my neighbours.
   Disagree 1 2 3 4 5 6 7 8 9
   Very Much
   Agree

8. I enjoy working in situations involving competition.
   Disagree 1 2 3 4 5 6 7 8 9
   Very Much
   Agree

Study 3 - English V2new 03/22/2006
17. Children should be taught to place duty before pleasure.

<table>
<thead>
<tr>
<th>Disagree</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very</td>
<td></td>
</tr>
<tr>
<td>Much</td>
<td></td>
</tr>
</tbody>
</table>

18. Without competition it is not possible to have a good society.

<table>
<thead>
<tr>
<th>Disagree</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very</td>
<td></td>
</tr>
<tr>
<td>Much</td>
<td></td>
</tr>
</tbody>
</table>

19. I feel good when I cooperate with others.

<table>
<thead>
<tr>
<th>Disagree</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very</td>
<td></td>
</tr>
<tr>
<td>Much</td>
<td></td>
</tr>
</tbody>
</table>

20. Some people emphasize winning; I am not one of them.

<table>
<thead>
<tr>
<th>Disagree</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very</td>
<td></td>
</tr>
<tr>
<td>Much</td>
<td></td>
</tr>
</tbody>
</table>

21. It is important to me that I respect decisions made by my groups.

<table>
<thead>
<tr>
<th>Disagree</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very</td>
<td></td>
</tr>
<tr>
<td>Much</td>
<td></td>
</tr>
</tbody>
</table>

22. I rather rely on myself than on others.

<table>
<thead>
<tr>
<th>Disagree</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very</td>
<td></td>
</tr>
<tr>
<td>Much</td>
<td></td>
</tr>
</tbody>
</table>

23. Family members should stick together, no matter what sacrifices are required.

<table>
<thead>
<tr>
<th>Disagree</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very</td>
<td></td>
</tr>
<tr>
<td>Much</td>
<td></td>
</tr>
</tbody>
</table>

24. I rely on myself most of the time; I rarely rely on others.

<table>
<thead>
<tr>
<th>Disagree</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very</td>
<td></td>
</tr>
<tr>
<td>Much</td>
<td></td>
</tr>
</tbody>
</table>
第九部份  探訪員填寫

請以下列標準去選出一個最能形容你同意或不同意下列句子的程度。

1. 我的快樂大部份取決於圍繞我身邊的人是否快樂。
  非常同意 1 2 3 4 5 6 7 8 9  非常不同意

2. 勝利就是一切。
   非常同意 1 2 3 4 5 6 7 8 9  非常不同意

3. 我通常會為顧全大局而犧牲個人利益。
   非常同意 1 2 3 4 5 6 7 8 9  非常不同意

4. 我會因其他人表現比我優勝而感到厭煩。
   非常同意 1 2 3 4 5 6 7 8 9  非常不同意

5. 我覺得與我群體中的人融合相處是重要的。
   非常同意 1 2 3 4 5 6 7 8 9  非常不同意

6. 我覺得我的工作表現比其他人優勝是重要的。
   非常同意 1 2 3 4 5 6 7 8 9  非常不同意

7. 我喜歡與鄰居分享小事物。
   非常同意 1 2 3 4 5 6 7 8 9  非常不同意

8. 我享受在有競爭的環境中工作。
   非常同意 1 2 3 4 5 6 7 8 9  非常不同意

Chinese questionnaire version 1 dated November 30, 2005
17. 應教導兒童去學會先完成任務才去享樂。
非常同意 〇 〇 〇 〇 〇 〇 〇 〇 〇 非常不同意
1 2 3 4 5 6 7 8 9

18. 沒有競爭，就不可能有一個好的社會。
非常同意 〇 〇 〇 〇 〇 〇 〇 〇 〇 非常不同意
1 2 3 4 5 6 7 8 9

19. 當我與其他人合作時，我感覺愉快。
非常同意 〇 〇 〇 〇 〇 〇 〇 〇 〇 非常不同意
1 2 3 4 5 6 7 8 9

20. 有些人著重獲取勝利，我則不然。
非常同意 〇 〇 〇 〇 〇 〇 〇 〇 〇 非常不同意
1 2 3 4 5 6 7 8 9

21. 我認為尊重我的群體的決定是重要的。
非常同意 〇 〇 〇 〇 〇 〇 〇 〇 〇 非常不同意
1 2 3 4 5 6 7 8 9

22. 我寧願信靠自己而非去依賴別人。
非常同意 〇 〇 〇 〇 〇 〇 〇 〇 〇 非常不同意
1 2 3 4 5 6 7 8 9

23. 一家人應團結一心，無論需要作出任何犧牲。
非常同意 〇 〇 〇 〇 〇 〇 〇 〇 〇 非常不同意
1 2 3 4 5 6 7 8 9

24. 我大部分時間依賴自己，罕有依賴別人。
非常同意 〇 〇 〇 〇 〇 〇 〇 〇 〇 非常不同意
1 2 3 4 5 6 7 8 9

Chinese questionnaire version 1 dated November 30, 2005
25. 父母及兒女必須在一起，時間越多越好。

非常同意 1 2 3 4 5 6 7 8 9 非常不同意

26. 對我來說，我個人的個性獨立於其他人是重要的。

非常同意 1 2 3 4 5 6 7 8 9 非常不同意

27. 照顧家庭是我的責任，就算是需要因此而作出犧牲。

非常同意 1 2 3 4 5 6 7 8 9 非常不同意

28. 對我來說，我個人的獨立性是非常重要的。

非常同意 1 2 3 4 5 6 7 8 9 非常不同意

29. 我是一個獨特的人，與眾不同。

非常同意 1 2 3 4 5 6 7 8 9 非常不同意

30. 為作一個成員，我尊重我群體中大部份成員所同意的決定。

非常同意 1 2 3 4 5 6 7 8 9 非常不同意

31. 我享受我的獨特性及與眾不同。

非常同意 1 2 3 4 5 6 7 8 9 非常不同意

32. 我認為先詢問親密朋友的意見才作出決定是重要的。

非常同意 1 2 3 4 5 6 7 8 9 非常不同意

Chinese questionnaire version 1 dated November 30, 2005
Appendix E

Cancer-Related Stressor Checklist (CRSC)
As noted in Chapter 2, there are 3 versions of the CRSC. The following presents version 1 of the
CRSC. Only Parts (a) and (c) of each item are relevant to this thesis.
I don't have as much information about cancer treatment as I need or want

5 a) Have you experienced this?  ○ Yes  ○ No

5 b) How stressful did you find it (or how stressful would it have been for you if you experienced it)?

<table>
<thead>
<tr>
<th>Not very stressful</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very stressful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5 c) What is the main cause of this stress that you have experienced?  ○ Tape recorded  ○ See notes

5 d) Which of the following best describes how you dealt (or how you would deal) with this situation? (Select all that apply)

- a  I trust the doctor's knowledge rather than researching things on my own.
- b  I feel encouraged because my doctor is enthusiastic about my treatment and my chances of recovery.
- c  I research treatment options to learn about what's best for me.
- d  I talk to people about their experience with cancer so that I can learn more about my treatment.

I need prompt medical attention

6 a) Have you experienced this?  ○ Yes  ○ No

6 b) How stressful did you find it (or how stressful would it have been for you if you experienced it)?

<table>
<thead>
<tr>
<th>Not very stressful</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very stressful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6 c) What is the main cause of this stress that you have experienced?  ○ Tape recorded  ○ See notes

6 d) Which of the following best describes how you dealt (or how you would deal) with this situation? (Select all that apply)

- a  I pray or meditate to calm my fears.
- b  I recognize that these things happen, I just have to accept it.
- c  I let my family know about the problem so that they can decide how they can help.
- d  I ask my doctors for help or go directly to the hospital.
第四部份  採訪員填寫

(錄音)  我感到焦慮或抑鬱。

1a) 你曾遭遇過上述情況嗎？  ○有  ○沒有

1b) 上述情況（若出現時）對你造成多大的壓力？（請選其中一項）

|  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|
|  |  |  |  |  |  |  |
| 壓力不太大 | 1 | 2 | 3 | 4 | 5 | 6 | 7 非常大壓力

1c) 在這個情況下，是甚麼因素令你感到有壓力呢？  ○錄音  ○請見附頁

1d) 以下哪些項目能形容你怎樣應付上述情況？若你從未遇過此情況，請假設你要面對

此情況，並選出全部能形容你怎樣應付此情況的項目。

○a 我向家人和朋友傾訴苦惱及尋求他們的支持。
○b 我試與他人做些事情來保持忙碌。
○c 我試保持良好的情緒和逃避負面的思想。
○d 我專注於檢驗結果，並希望能看到我的病情有所改善。

我醒覺到自己可能會死亡。

2a) 你曾遭遇過上述情況嗎？  ○有  ○沒有

2b) 上述情況（若出現時）對你造成多大的壓力？（請選其中一項）

|  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|
|  |  |  |  |  |  |  |
| 壓力不太大 | 1 | 2 | 3 | 4 | 5 | 6 | 7 非常大壓力

2c) 在這個情況下，是甚麼因素令你感到有壓力呢？  ○錄音  ○請見附頁

2d) 以下哪些項目能形容你怎樣應付上述情況？若你從未遇過此情況，請假設你要面對

此情況，並選出全部能形容你怎樣應付此情況的項目。

○a 我作好一個計劃來確保家人的福利在我去世後會被照顧。
○b 我與好朋友談及我的恐懼。
○c 我往好處看自己的狀況。
○d 我將所有精力放在自己能戰勝癌症的積極思想上。
我所需要或想有关癌症治疗的资讯不足。

5a) 你曾遭遇过上述情况吗？ 〇有 〇没有

5b) 上述情况（若出现时）对你造成多大的压力？（请选其中一项）

〇压力不太大 1 〇 2 〇 3 〇 4 〇 5 〇 6 〇 7 〇非常大压力

5c) 在这个情况下，是甚么因素令你感到有压力呢？ 〇录音 〇请见附页

5d) 以下哪些项目能形容你怎样应付上述情况？若你从未遇过此情况，请假设你要面对此情况，并选出全部能形容你怎样应付此情况的项目。

〇a 我相信医生的知识，而非靠自己去寻找资料。
〇b 我因医生对我的治疗和痊愈机会很热衷而感到鼓舞。
〇c 我搜集有关各种治疗方法的资料来了解甚么对我是最好的。
〇d 我与其他病人谈论他们的经验，好让我能从中对我的治疗加深了解。

6a) 你曾遭遇过上述情况吗？ 〇有 〇没有

6b) 上述情况（若出现时）对你造成多大的压力？（请选其中一项）

〇压力不太大 1 〇 2 〇 3 〇 4 〇 5 〇 6 〇 7 〇非常大压力

6c) 在这个情况下，是甚么因素令你感到有压力呢？ 〇录音 〇请见附页

6d) 以下哪些项目能形容你怎样应付上述情况？若你从未遇过此情况，请假设你要面对此情况，并选出全部能形容你怎样应付此情况的项目。

〇a 我用祈祷或冥想来平复自己的恐懼。
〇b 我认识到这些事情会发生，我只能去接受它。
〇c 我把问题告诉家人，以便他们决定如何能协助我。
〇d 我要求医生帮忙或直接往医院。

Chinese questionnaire version 1 dated November 30, 2005
7a) 你曾遭遇過上述情況嗎？ 〇有 〇沒有

7b) 上述情況（若出現時）對你造成多大的壓力？（請選其中一項）

〇 壓力不太大 1  〇  2  〇  3  〇  4  〇  5  〇  6  〇  7  非常大壓力

7c) 在這個情況下，是甚麼因素令你感到有壓力呢？ 〇錄音 〇請見附頁

7d) 以下哪些項目能形容你怎樣應付上述情況？若你從未遇過此情況，請假設你要面對此情況，並選出全部能形容你怎樣應付此情況的項目。

〇 a 我提醒自己：“當我感到別人或許不明理時，我最好別告訴他們我的病況”。
〇 b 我嘗試去想一些在我生命中較為幸運的事。
〇 c 我如常外出並與人談話，縱使他們可能因我的出現而感到不安。
〇 d 我與那些能激勵及鼓勵我的人在一起來避免傷感或意志受挫。

8a) 你曾遭遇過上述情況嗎？ 〇有 〇沒有

8b) 上述情況（若出現時）對你造成多大的壓力？（請選其中一項）

〇 壓力不太大 1  〇  2  〇  3  〇  4  〇  5  〇  6  〇  7  非常大壓力

8c) 在這個情況下，是甚麼因素令你感到有壓力呢？ 〇錄音 〇請見附頁

8d) 以下哪些項目能形容你怎樣應付上述情況？若你從未遇過此情況，請假設你要面對此情況，並選出全部能形容你怎樣應付此情況的項目。

〇 a 我嘗試不向最壞處想。
〇 b 我完全讓醫生決定什麼療法對我最好。
〇 c 我向醫生尋求意見。
〇 d 我倚賴家人和朋友向我提供新療法的資料。  （終止錄音）

Chinese questionnaire version 1 dated November 30, 2005
Appendix F

Memorial Sloan-Kettering Symptom Assessment Scale (MSAS), revised version
Below are some symptoms that people may experience. For each one, please indicate whether you've experienced the symptom **IN THE PAST WEEK** by selecting YES or NO.

During the **past week**, did you experience:

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of energy</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Cough</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Nausea</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Feeling drowsy</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Feeling bloated</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Problems with urination</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Vomiting</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Sweats</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Itching</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Difficulty swallowing</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Mouth sores</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight change</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Constipation</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Swelling of arms and legs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changes in skin</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Fevers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Muscle or bone aches</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jaundice</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Dry eyes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stiff joints</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hair loss</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tremors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Puffy face</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
第三部份  ○ 採訪員填寫

以下是一些很多人都曾感受過的症狀。請在每一項旁，選出「有」或「沒有」去顯示在過去的一個星期內，你曾否感受過該症狀。

在過去的一個星期內，你曾否感受過：

<table>
<thead>
<tr>
<th>症狀</th>
<th>有</th>
<th>沒有</th>
</tr>
</thead>
<tbody>
<tr>
<td>痛楚</td>
<td></td>
<td></td>
</tr>
<tr>
<td>口腔潰爛</td>
<td></td>
<td></td>
</tr>
<tr>
<td>沒有精力</td>
<td></td>
<td></td>
</tr>
<tr>
<td>體重改變</td>
<td></td>
<td></td>
</tr>
<tr>
<td>咳嗽</td>
<td></td>
<td></td>
</tr>
<tr>
<td>便秘</td>
<td></td>
<td></td>
</tr>
<tr>
<td>口乾</td>
<td></td>
<td></td>
</tr>
<tr>
<td>手腫腳腫</td>
<td></td>
<td></td>
</tr>
<tr>
<td>反胃</td>
<td></td>
<td></td>
</tr>
<tr>
<td>皮膚有異象</td>
<td></td>
<td></td>
</tr>
<tr>
<td>昏昏欲睡</td>
<td></td>
<td></td>
</tr>
<tr>
<td>發燒</td>
<td></td>
<td></td>
</tr>
<tr>
<td>腹脹</td>
<td></td>
<td></td>
</tr>
<tr>
<td>肌肉痛或骨痛</td>
<td></td>
<td></td>
</tr>
<tr>
<td>小便有問題</td>
<td></td>
<td></td>
</tr>
<tr>
<td>黃疸</td>
<td></td>
<td></td>
</tr>
<tr>
<td>嘔吐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>眼乾</td>
<td></td>
<td></td>
</tr>
<tr>
<td>氣促</td>
<td></td>
<td></td>
</tr>
<tr>
<td>關節彎硬</td>
<td></td>
<td></td>
</tr>
<tr>
<td>腹瀉</td>
<td></td>
<td></td>
</tr>
<tr>
<td>脫髮</td>
<td></td>
<td></td>
</tr>
<tr>
<td>出汗</td>
<td></td>
<td></td>
</tr>
<tr>
<td>發抖</td>
<td></td>
<td></td>
</tr>
<tr>
<td>痤瘡</td>
<td></td>
<td></td>
</tr>
<tr>
<td>面部浮腫</td>
<td></td>
<td></td>
</tr>
<tr>
<td>難於吞咽</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Chinese questionnaire version 1 dated November 30, 2005
Appendix G

Taxonomy of stressor appraisals

Note: underlined [sic] sections are reproduced verbatim from Chinese transcripts; (I: …) = Interviewer’s comment or questions
<table>
<thead>
<tr>
<th>Stressor appraisal name and description</th>
<th>Exemplar(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Abrupt change to lifestyle</strong></td>
<td>• “...the fact that overnight that you’re not going to just be able to pick up and go and do whatever it was you could the same time last month or the same time last year.”</td>
</tr>
<tr>
<td>Sudden change to one’s lifestyle</td>
<td></td>
</tr>
<tr>
<td><strong>2. Afraid of death</strong></td>
<td>• “But it’s just more about being afraid of what that means and what that is.”</td>
</tr>
<tr>
<td>Fear associated with the meaning and experience of death, e.g. slow and lingering death, and what happens after death</td>
<td>• “...don’t wanna die.”</td>
</tr>
<tr>
<td></td>
<td>• “I, I don’t know what happen after this life...”</td>
</tr>
<tr>
<td></td>
<td>• “...just knowing that it’s all over and it’s permanent.”</td>
</tr>
<tr>
<td><strong>3. Allowing others to know about vulnerability (or anxiety about doing this)</strong></td>
<td>• “...having to explain that you’re not perfect. Having to explain that you, you know, you have a problem when everybody thinks, well, you’re, you know, everything’s, everybody’s healthy...”</td>
</tr>
<tr>
<td>Letting others know that you are vulnerable or in need (or anxious about doing it)</td>
<td>• “...because I had to, uh I had to open and take down the tough facade...Like in the case of my uh children, well they looked to me for support, and I had to somehow look to them for support. Dad’s not invincible anymore.”</td>
</tr>
<tr>
<td></td>
<td>• “...trying to be strong about it because you don’t want people seeing your emotional side of things.” (Note: It means that “I’m” weak if others see his/her emotional side of things.)</td>
</tr>
<tr>
<td><strong>4. Anticipating loss of valued relationships after death</strong></td>
<td>• “...when people are told that they have cancer or may have cancer, it’s a bit like a bereavement because, you know, a separation from a, a loved one or something.”</td>
</tr>
<tr>
<td>Anticipation of loss of relationships after death</td>
<td>• “Because I have a husband, 4 boys, and 4 grandchildren that I wouldn’t want to leave.” (Note: Context implies possible death of participant e.g., response for stressor appraisal “I realized I may die.”)</td>
</tr>
<tr>
<td></td>
<td>• “You don’t want to leave your family, you don’t want to leave your friends.” (Note: Context implies possible death of participant e.g., response for stressor appraisal “I realized I may die.”)</td>
</tr>
<tr>
<td></td>
<td>• “...the scary part is that you’re not gonna be able to see the people you love...”</td>
</tr>
<tr>
<td>Stressor appraisal name and description</td>
<td>Exemplar(s)</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>-------------</td>
</tr>
</tbody>
</table>
| 5. Anticipating or receiving unfavourable test results or news | • “…waiting for the next shoe to drop…” (Note: It’s an idiom meaning waiting for the next bad thing to happen.)
| | • “I knew something was serious but, and I sort of figured it was cancer. I was just waiting for the ball to drop.” (Note: It’s an idiom meaning waiting for the next bad thing to happen.)
| | • “…always expecting the worst and thinking that it was going to be bad news.”
| | • “Anxious because you’re also fearful that the results could be not to your best interest.”
| | • “…when I went for my check-up on-in May, I really didn’t think there was anything wrong. But then after they found something wrong, and in the tests I’ve had since then, you know I’ve been quite anxious about the results.” (Note: Previous exposure to negative test results triggers anxiety before each test result comes back.)
| 6. Anticipating treatment and side effect | • “[Doctor’s name] explained that, you know, because of where it’s located in my mouth, um, they might have to cut my lip and my chin down to, from my lip down to my chin, just so they could get greater access to the area that they had to operate on. And um, that, that was not very good news and I almost passed out.”
| | • “I’m terrified of surgery so I knew I was having surgery, so that was probably my biggest anxiety.”
| | • “…you were dreading going to the hospital because you know you’re getting this medication and you would feel sick afterwards and there’re days you just didn’t even want to go. OK, just worrying about feeling sick afterwards...”
| | • “I was warned before the treatment um, and I was told about all the side effects and the symptoms I’m going to experience. So I was warned about that too.” (Note: “warned” doesn’t equal to “thinking about it” directly, but talking about it is an indication of “thinking about it”)
| 7. Being different from others | • “…when you are sick, you would feel that you are, a bit different from others, I guess this difference is my stress, right.”
| | • “Because it would make me feel different, not normal.” (Note: This quote fits here because participant did not say that he/she feels different from him or her “self”, but rather from the general “norm”.)
| | • “...maybe I was outside the norm now, you know like, like you’re normal if you don’t have cancer, but if you have cancer you’re in another group of human beings. So I’ve been now taken out of the regular group and I wondered if these people thought like that ‘cause I had thought like that.” (Note: Emphasis on not fitting with the normal group, i.e., “out of regular group.”)
<table>
<thead>
<tr>
<th>Stressor appraisal name and description</th>
<th>Exemplar(s)</th>
</tr>
</thead>
</table>
| 8. **Being separated from family**     | • “And being away from my family, I had to be in isolation for three days.”  
• “I think being overseas, away from my family, uh, was really stressful.” |
| Being separated from family            |             |
| 9. **Bored by repetition**             | • “I get tired of hearing the same thing day in and day out...I had a year of this stuff. And it’s the same thing every time I go in, same old thing.” |
| Patient expresses frustration that the medical information or activities is repetitious and uninteresting |             |
| 10. **Burdensome to search for medical information** | • “It takes uh, it takes uh my time and to do some research, and get into it...”  
(Note: Thought quote did not mention psychosocial strain, it is clearly burdensome for the individual)  
• “…it would take more energy to search out answers…if it meant going on the, on the Internet I would, if it meant asking friends who have cancer I would, if it meant going to a centre to find out more I would, if it meant getting a second opinion I would and all that you know, would be, would be frustrating and stressful because you had to clear it up...Extra work.” |
| Need to search for medical information adds incrementally to psychosocial strain |             |
| 11. **Cancer diagnosis**               | • “…the fear of being diagnosed…” (Note: Fear triggered by diagnosis of cancer.)  
• “Being the fact that I had cancer...” |
| Being diagnosed with cancer            |             |
| 12. **Cancer diagnosis or death is premature** | • “I felt that I was still young, shouldn’t be so soon...that is, hoping that...it could be cured, I wouldn’t die.”  
• “I think it’s the shock that, you know, you’re young and you don’t think that could happen to you.”  
• “…myself being so young and raising two children, how can I have cancer at the same time...” |
| Feeling that life may end prematurely (getting cancer /death at this point is developmentally off-time) |             |
| 13. **Cancer recurrence**              | • “…the main cause of the stress was the fact that this skin cancer kept returning and um, I was probably told by physicians who did the first series of minor operations um, that that should be it, that um I’m cured, that I don’t need to come back. But I kept coming back, and uh, eventually that became um stressful.” |
| Diagnosis of cancer recurrence        |             |
| 14. **Cannot rely on other for support** | • “I think it’s being… not able to express to other people openly how you feel about it. Without…’cause you know they’re going to be upset. So then they’re not any help to you, they’re actually a liability because they’re as upset as you are and not helpful.”  
• “I didn’t think they’d understand, so I didn’t bother asking for any type of emotional support.”  
• “It’s, it’s partly uh an ethnic base, it, it, the people that I come from are very unemotionally involved in, in personal things like that so as a result, that, that situation occurs and does not help an already stressful situation.” |
<table>
<thead>
<tr>
<th>Stressor appraisal name and description</th>
<th>Exemplar(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>15. Changes in identity</strong>&lt;br&gt;Changes in concept of him/herself due to disease, treatment, and/or other’s perception of oneself. Refers to changes in concept of self, i.e. “Who I am”, not to be confused with sensory/perceptual experience of self.</td>
<td>• “I didn’t look like me, I didn’t know who I was going to be again.”&lt;br&gt;• “…not being the same person that I was. Uh, taking away the man that I was.”&lt;br&gt;• “That is, relatively. But I’m still not…a hundred percent [sic], that is…a com-com-com-complete person.”&lt;br&gt;• “That sense of self it’s the you know, it starts to diminish. Uh, and you know I can’t go out, I can’t eat, you know I can’t talk without pain. I can’t you know, do all those things that I normally could do and so the longer it went on, the less like me I felt and the more stressful it got.”</td>
</tr>
<tr>
<td><strong>16. Changes in social status</strong>&lt;br&gt;One’s position or role within a social hierarchy has altered</td>
<td>• “It is um, it is having um, an important role…in the, in my workplace. Uh, I ha-I think I’ve lost it I was away for over a year. I was away for abo-uh, I would say about fifteen months. And then um, when before my, my, my cancer, before my treatment when I was there, um, I, I felt that I had a very um, I would say uh, important role in the operation of the branch. And now that I’m back at work I find that I am just uh, a nobody. I’ve been uh, given another set of job responsibilities that has no, um, has no um, incentive for me. So I think that that’s really stressful.”</td>
</tr>
<tr>
<td><strong>17. Changes to or unable to achieve goals</strong>&lt;br&gt;Cannot accomplish goals or having to adjust original goals (goal is defined as specific objectives or outcomes that one deems important to accomplish in life e.g., developmental milestones)</td>
<td>• “...the main thing is that you wouldn’t accomplish what you were set out to do. Um, I was brought up, I guess to be in the workforce, sort of thing and I-I say about fifteen months. And then um, when before my, my, my cancer, before my treatment when I was there, um, I, I felt that I had a very um, I would say uh, important role in the operation of the branch. And now that I’m back at work I find that I am just uh, a nobody. I’ve been uh, given another set of job responsibilities that has no, um, has no um, incentive for me. So I think that that’s really stressful.”&lt;br&gt;• “…lack of fulfillment. Not seizing certain opportunities in my life. And not completing certain, certain goals that I had set for myself.”&lt;br&gt;• “…the realization that you may not accomplish everything that you had planned to accomplish during a lifetime.”&lt;br&gt;• “Because uh, when I had ovarian cancer, I was told I couldn’t have children – any more children, even though I already had three, I still had wanted another one, but because of having ovarian cancer, I couldn’t have it any…any more children, so I found that stressful...”</td>
</tr>
<tr>
<td><strong>18. Coerced into treatment</strong>&lt;br&gt;Patient was pressured to accept treatment to which he/she is opposed</td>
<td>• “I guess not uh, not wanting to go through with the surgery and the um, the actual, um, treatment. Yup. I’m more of a natural person. I like to take more of a natural approach to things and I felt pressured, pretty much from the doctors and from family.”</td>
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<td><strong>19. Communicating diagnosis to loved ones</strong>&lt;br&gt;Informing loved ones of one’s cancer diagnosis</td>
<td>• “I think my main concern at that time wasn’t about me it was about having to tell my family. And how they would react.”&lt;br&gt;• “…how do I explain this to my children, how do I deal with that?”&lt;br&gt;• “I think the stressful part of it was um, having to share with people that I care about that there was something wrong with me. I was worried about them being upset or stressed.”</td>
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<td>20. <strong>Concern about making my doctor angry</strong>&lt;br&gt;Anxious that patient’s behaviour (or lack of) may annoy or frustrate the doctor</td>
<td>“...make the doctors frustrated with you too for not following instructions.”</td>
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<td>21. <strong>Concern about one’s health</strong>&lt;br&gt;Concern about one’s health</td>
<td>“I lost a lot of weight from not eating ‘cause I just couldn’t keep things down so I was worried about my health that way.”</td>
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<td>22. <strong>Concern about what others are thinking</strong>&lt;br&gt;Worried about others’ thoughts about oneself</td>
<td>“...it’s kind of embarrassing too, because um I don’t have that great bladder control. So every time I’d vomit, I’d also wet myself, oh and I’d wet the bed and that was really embarrassing. You know, having the doctors come in, and my bed’s all wet, that was really embarrassing.”&lt;br&gt;“Well, it’s a little embarrassing when you can’t talk, normally, to people. You have to speak to them, in my case, sort of a whisper.”&lt;br&gt;“...the cancer protruded out like a golf ball. So it was sticking out. So it’s kinda weird. Carrying this little golf ball around all the time and people’d be like, ‘What is up with that?’”&lt;br&gt;“I was more distressed about this idea that I might have some laryngeal wart that’s linked to the Human Papilloma Virus. And that people would think, I don’t know, that uh, you know, I’d got some strange venereal disease of the throat. Um, and that I was a loose woman, you know. And nothing could have been further from the truth, you know.”</td>
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<td>23. <strong>Concern how family would cope after one dies</strong>&lt;br&gt;Worried about how the family will carry on with life after one dies. (Note: When response emphasizes how family will manage in the absence of the deceased loved one, assign it to “Concerns how family would cope after one dies”. When response emphasizes the concern that one will be unable to provide care for loved ones, assign to “Threat of unable to care for loved ones if one dies”)</td>
<td>“...it’s not so much whether I’m going to live, I don’t care truthfully as long as somebody’s going to look after [grandson’s name]; that’s all I worry about okay. It worries me to a point but I mean it wasn’t something that I felt worried that much I was more worried about who was going to take [grandson’s name], that’s all I worry about.”&lt;br&gt;“Why was I stressed because my daughters were, one was still in school, well actually both of them were still in school, so it was stressful, how they gonna cope with it, how they gonna carry on if something happens to me or. It was very stressful.”&lt;br&gt;“...if I wasn’t around, it would be, obviously it would be hurtful to them, so that’s the most I was concerned about.”</td>
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<td><strong>24. Concern that the health care professionals cannot fulfill role expectations</strong>&lt;br&gt;[Patient has impression that health care professionals cannot perform role competently (e.g. diagnosis and treatment errors and insufficient care), or does not have the necessary expertise]</td>
<td>• “Not entering into like, the healthcare system is not a supportive system. I had concerns about what that was going to uh, be like. Um...[sigh] going into hospital and uh, uh, was I going to be ignored? Was I going to be attended to? Uh, yeah, those things.”&lt;br&gt;• “...because if I didn’t understand what they were doing or what they were saying, I would wonder, is it, um, am I seeing the right doctor or am I not understanding what they’re saying. Am I in the right, am I seeing the right healthcare providers.”&lt;br&gt;• “...because they are professionals, they have professional codes of conducts. So there’s no reason, they, that is, their advices would be unclear, unclear, right? They ask me to leave, without knowing anything. That means I’d think, ‘That is, what the heck? That is, this is your profession, there’s no reason why you would explain it so badly.’”&lt;br&gt;• “...it’s stressful because, you’re, you’re unsure, you know. You realize you have a healthcare professional there that’s making a recommendation but you don’t know him and you know, do you trust him or, you know. I know very little about oral cancer and obviously this guy does and he’s making a recommendation to deal with it so it’s, it’s, it’s a trust relationship with your doctor, that’s he’s doing the best thing for you, for you.”&lt;br&gt;• “I guess just needing to speak to them to get all the answers from them because it was so much, uh not misinformation, but there’s so much on uh explaining or unknown things, with my initial diagnostics. And it seemed to me like there was, there was confusion on the doctor’s behalf and really what was going on. So there was stress there because it was kind of like well, ‘I don’t know.’ And the professional doesn’t know, so you know that can be very stressful situation to feel like this is somehow out of everyone’s hands.”</td>
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<td><strong>25. Concern whether one’s decision may be wrong</strong>&lt;br&gt;[Questions that one’s decision (past, present, or future) will lead to the best outcome]</td>
<td>• “Because I was afraid of make [sic] the wrong decision [sic].”&lt;br&gt;• “I wouldn’t know whether my decision would be right.”</td>
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<td><strong>26. Concerns not taken seriously by health care professionals</strong>&lt;br&gt;[Feeling that concerns were dismissed or not understood by health care professionals]</td>
<td>• “It was more that we were being told that what I was experiencing isn’t what I was experiencing. Because we tried to make it so clear that the pain was excruciating but people didn’t seem to believe that.”&lt;br&gt;• “The other issues he didn’t take them as a significant problem [sic].”&lt;br&gt;• “...I would always keep talking about how rough my-my throat feels you know, and they say, ‘Well, it is dry you know.’ You know, and that to me isn’t answering – [begins to laugh] I want a solution.”</td>
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<td>27. <strong>Concerns or stress triggered by others’ worries</strong>&lt;br&gt;Others’ concerns (or excessive worries) about patient’s illness and/or related losses lead to his/her own concerns or worries</td>
<td>• “Well if they’re worried, I mean if they think it’s serious then you, you’re obviously going to worry yourself. Because you think...If that, if they think, ‘Oh my goodness, she’s got cancer and she’s really sick.’ Then you think, ‘Well, I better worry more than I am.’”&lt;br&gt;• “...everyone thinks of it as such a death sentence, and so you’re aware of their fear and it’s, it’s scary. Like it makes you, makes you more scared.”</td>
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<td>28. <strong>Conflicted over expressing support needs</strong>&lt;br&gt;Feeling conflicted over expressing one’s need for emotional support</td>
<td>• “You have a right to feel angry or feel cheated or to be sad or um, depressed or and all of those things. When I think a lot of times, you know, people sort of don’t feel like they have permission to, to show the negative side of the disease...”&lt;br&gt;• “...you need people but you don’t like to, I don’t like to um, make them stressed out as well.”&lt;br&gt;• “I had a hard time uh, expressing my feelings, uh maybe involving them in my emotion...in my, in my feelings and explaining correctly to them um, that I needed support, so they didn’t really understand that I needed that, and I found it stressful because I wanted them just to know. I didn’t wanna have to explain it.”</td>
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<td>29. <strong>Conflicted over giving up harmful behaviour</strong>&lt;br&gt;Patient feels conflicted over having to give up a pleasurable but harmful behaviour e.g. smoking</td>
<td>• “‘Cause I can’t quit ‘cause I don’t wanna quit. ‘Cause I love smoking but I have to and it’s that, inner battle.”</td>
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<td>30. <strong>Conflicted over support from family and friends</strong>&lt;br&gt;Feeling conflicted over the supportive gestures from family members or friends or receiving more support than desired</td>
<td>• “…of course, you wanted people to care about you. But, if there are too many calls, that is, it’d affect you. Yep, being disturbed, or you had to….err deal with them because they were compassionate, right?”&lt;br&gt;• “…they’re getting involved in my business which I guess I can understand but now, you know what, I, part of me wants to just say…forget about it. I don’t want it to be such a big thing. And I don’t want to blow it out of proportion.”</td>
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| **31. Conflicting information undermines one's hope**<br>Receiving inconsistent information that contradicts that one is cancer-free | • “...the fact that I was told one thing then it was changed around without...without any type of a preparation. It was a matter of fact, I don’t know what the mix up was. I think that, obviously it needed it because it was a little bit deeper than he thought, but he didn’t think of that before he told me, so I found that very stressful.”  
• “...before my…my first major operation, the medical opinion was that I would not need radiation but when I came out of the aesthetic, uh, pretty much not long after that, the…the resident surgeon told me that in fact, they did want me to go through radiation. And that was just, that was probably the worst example of getting your hopes.” |
| **32. Contact with others exacerbates one's fears**<br>Context sensitizes to the threat of cancer e.g., seeing other cancer patients, meeting with doctor, others’ past experiences with cancer | • “The biggest source I was, that is heard other people say, after they finished their treatment [sic], how they suffered when they got back, how they suffered. Right, so I, I would go, ‘Crap!’ Scared that I myself, so after I finished it then, ‘Crap.’ This time I didn’t, the next time I finish, would there be as much suffering? Would there be side effects like theirs? Would their symptom [sic] show up afterwards?”  
• “You’ll see someone else who has cancer, my neighbour across the street now has cancer and it never leaves you.”  
• “Because I…my older brother also had this disease. Because he passed away already. I was afraid that I’d follow in his footsteps.”  
• “…a lot of these things come back a few days or weeks before I had my every-two-month check-up.”  
• “It is to a certain extent because you’re still in cancer clinic and you still see the suffering and all that. Yeah, I’m ok but, and I’m looking at them and I’m thinking, ‘God, I’m lucky.’ And what if and yeah, what are they going through type thing, so…there was still a certain amount of stress.”  
• “…going on the Internet and, uh, on the chat groups for the American Cancer Society and speaking to other people who have had the same cancer and hearing their horror stories.” |
| **33. Continuing to fulfill family responsibilities despite need for personal care**<br>Continuing to fulfill family responsibilities despite need for personal care | • “…just the fact that I had to make arrangements for my husband while I was in hospital, and he’d have to be looked after somehow...”  
• “…if you’re not there for supper or anything it’s hard. I have to get everything prepared, he won’t do any cooking so [mumble]. And those are things you can’t get done if you’re sick. You don’t feel, you do it but really you just wanna go lie down.” |
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| 34. Couldn’t live normally                | • “…because I used to teach. That is, I suddenly have nothing to do, it’s like…that is I didn’t know how…[laugh] to live my life. That is I have to readjust.”  
  Unable to continue with normal life, e.g., limited range of activities, limited level of participation, and/or cannot participate in some pre-cancer activities (including lifestyle changes)  
  • “The inability to conduct the lifestyle that I am used to and like to. To do the things I like to do basically.”  
  • “…the sense your life was ah starting to go downhill you know, kind of, wouldn’t be able to do certain things…”  
  • “…you’ve never watched it on the sidelines, right. You want to be in the game and play. In a, in a real sense as well as a uh metaphorical sense.”  
  • “Because I wouldn’t, I-I’m not able to perform like I used to do, do the same work, uh, I can’t eat and enjoy eating, and the same thing, can’t enjoy eating, can’t work the way I used to work.”  
  • “You are a normal person, your life should be unrestrained, so then all of a sudden you find out that you have cancer…more or less your lifestyle before your cancer, there would be changes. Change for yourself, change for the family, it is still a change.. Because your lifestyle cannot be the same as before, when you do what you want to do, it would become a stress.” |
| 35. Diagnosis occurred in context of independent stressful life events | • “…the diagnosis came at a real bad time for me. I had just lost my father…”  
  Received cancer diagnosis at the same time as independent life stressors  
  • “…actually the day that I found out that I have cancer was the same day that um, our adoption became legal. And then after that I had a year of the Children’s Aid coming in and peeking in and seeing what we’re doing, once a month they would come.”  
  • “I’d just had a baby, who at the time of diagnosis was just about a month.” |
| 36. Difficulties with eating | • “…I’ve not been able to uh get back my taste buds as much as I would like with the dry mouth, eating is very difficult, a lot of foods I can’t eat.”  
  Experience challenges in eating  
  • “It’s very stressful because you…you can’t eat properly, you can’t eat, you’re limited to what you can eat, only liquids and that was tough.” |
| 37. Difficulties with motivation | • “…’cause I just don’t have any uh drive to…I don’t…I don’t care anymore.”  
  Difficulties in finding or maintaining a reason to do things  
  • “It was all I could do to get through the day and I just couldn’t wait to get home to go to bed. And it was very stressful because you didn’t have the energy to do anything else. Or you didn’t want to do anything else.” |
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<td><strong>38. Difficulties with speech or hearing</strong>&lt;br&gt;Loss or reduction in one’s ability to speak or hear (or fear of), including resulted communication challenges</td>
<td>• “And with not being able to talk it’s hard, you know, to uh communicate with people when you can’t speak.”&lt;br&gt;• “Yeah, that’s right, and even to hear – I couldn’t even hear her.”&lt;br&gt;• “…likely my communication, if they ignored me it would be because they can’t understand me and that would be what would stressed me out…”&lt;br&gt;• “…the possible voice, loss of my voice. Because the cancer had, uh, surrounded my vocal cords. And I was told I would probably not be able to speak following the surgery.”</td>
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<td><strong>39. Difficulty accessing medical expertise</strong>&lt;br&gt;Problems in acquiring needed medical information and expertise and/or access to health care professionals, including threat of</td>
<td>• “Had few contacts with the doctors, very few contacts with the health care organizations. What is the process, because the process was also new for me. Could not find, the most difficult thing was that I felt I could not find help.”&lt;br&gt;• “I think that knowing that the doctors are not necessarily always available to you when, you feel they, that you need somebody.”&lt;br&gt;• “When I was in the hospital, I was having some, not major, but, but complications. And it was extremely difficult to get a hold of the residents or the doctors and I didn’t find uh most of the nurses were very knowledgeable and helpful. So it was the sense of uh not…uh I felt as if, if I didn’t get on top of things they were going to get worse and worse. And nobody seemed to know or be available to try to help figure out how to get on top of things. So you had that incredible panic of I’m going to get worse and worse here and nobody’s doing anything about it. So that was what was very difficult.”&lt;br&gt;• “Uh trying to communicate properly with the doctor given uh the newness of the situation to me and his time constraint. They always seem to be in a rush.”</td>
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<td><strong>40. Difficulty in recapturing lost time</strong>&lt;br&gt;Patient does not feel that he/she can recapture the lost time</td>
<td>• “I feel like I’ve lost 5 years out of my life. Umm not being able to do the day to day things that I would normally do. And ahh now I’m older so it’s more difficult to recapture… those 5 years.”</td>
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<td><strong>41. Difficulty understanding medical information</strong></td>
<td>• “I liked to pretend I heard everything. And I’d question back again. Like, like I would tell them I forgot already. And when you get to a certain age you do forget pretty quick. So I’d let it slide and then hopefully it would come up again.” (Note: the issue is with patient’s memory)</td>
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<td>• “…you may not always comprehend what your doctor is telling you…about some medical terms.”</td>
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<td>• “…the stress associated with waiting for new information when you know I already went and got some but now I don’t really know how to interpret it until you give me the test results.”</td>
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<td>• “Just a little annoying that it’s my own fault, not having somebody with me or paying more attention.”</td>
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<td>• “I would think that maybe I wasn’t uh, intelligent enough to understand what they were talking about. I think that would really be frustrating.”</td>
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<td><strong>42. Disease as punishment</strong></td>
<td>• “If it is your turn, you just were, that is to say, for example, if you have to die, just, so, that is to say, perhaps you commit a sin during your past life/past generation. If you are not dead yet, that is to say, God has given you a very small punishment.”</td>
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<td><strong>43. Disrespectful or insensitive health care professional behaviour</strong></td>
<td>• “…when they didn’t explain things to you and they treated you like you were stupid, umm or wouldn’t understand cause they are smarter then you or something…”</td>
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<td>• “You’re with a doctor who is often training someone beside them, you lose your uh the one-on-one with that person and you lose that connection…”</td>
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<td>• “…the most frustrating part about it was they come in every 2 hours and shine a light in your face, “Are you asleep [patient’s name]?””</td>
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<td>• “At that time, if you are with, tell your doctors, you know us Chinese people, as we eat, we like to talk at the same time, it is the same at home, right? Eating is a type of socialization. So then, this situation, you tell your foreign doctor, that is to say, at work, eating, or eating out, I couldn’t talk after I eat, a very simple answer is…the answer that is, ‘Really? When you eat, you’re not suppose [sic] to talk.’ Ok ha ha. But then this is a type of stress.”</td>
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<td><strong>44. Do not understand other’s response</strong></td>
<td>• “…why should people feeling sorry for me?”</td>
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<td><strong>45. Doctor presents worst case scenario</strong></td>
<td>• “…it was hearing the worst case that made me anxious because they said I may lose my voice completely or be speaking with one of those - electronic…”</td>
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<td>Doctor's uncertainty about prognosis and treatment outcome</td>
<td>• “…when you talked to your doctor, they gave you err, could gave you some sort of confidence, so to let you know, err, how far along your treatment progressed to right now, was it up to, to a correct direction. So if I didn’t have their…their response, like so, so became unsure, then you would only, that is your heart would be rather uncomfortable.”</td>
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<td>Doubts about recommended treatment</td>
<td>• “I was told I needed to have surgery and I just um you know I was really questioning whether I need to though, I still just kind of felt anxiety about doing what he recommended.”</td>
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| Effort and resources spent on treatment do not lead to desired results | • “I’ve spent a great deal of money…even sold my house, really. Really, didn’t [mumble]. What’s more, the results coming back were not necessary…okay [sic]. It was the biggest concern. I think, I dumped so much money into this and it may not necessary be okay [sic], although no one can be sure [sic] that it must be okay [sic].”
• “Difficult to come to terms with the fact that we’re supposed to be fixing this thing but ahh made matters worse, certainly coming to terms with the fact that it was a necessary ahh step but not specifically you know what you would choose if it didn’t make matters better overnight. You have to go through yet another umm the side effects are such that you now have a, a separate and a parallel ahh recovery process physically as opposed to what you were working with in the first place.” |
| Emotional burden on family and friends | • “Just the fact that they were concerned, right. Inconveniencing them. I don’t like to inconvenience people.”
• “I guess seeing the stress that other people were put under. Uh, especially my, you know, close, people that were closest to me. I-I saw how it, it uh, affected them.”
• “I don’t want people to worry about me.”
• “…the most stressful thing was uh having to deal with my parents, who (a) didn’t really understand what I was going through, and (b) uh felt helpless watching me go through this…”
• “…because they have a lot on. Particularly the ones that I see the most, and they have very big stress in their lives and they don’t need it, as far as worrying about me also.” |
<p>| Enduring side effects | • “…it was stressful because you know you’re just kind of going through that period of time and, and waiting to come out the other side.” |</p>
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<td>51. Facing changes due to cancer</td>
<td>“...there is an element of annoyance, ahh frustration no but annoyance in that ahh you’re again you’ve gone from no maintenance to-to a list of things that have to be done...”</td>
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<td>Awareness that his/her life will change as a result of cancer diagnosis</td>
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<td>52. Facing disease or treatment alone</td>
<td>“…it’s like, it’s like you need someone there, by your side, that is to support you, like that. Right. But of course, in the end, you’re on your own when you undergo treatment, like that.”</td>
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<td>Dealing with disease and/or treatment on his/her own</td>
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<td>(including feelings of loneliness and isolation)</td>
<td>“I had just lost my father and I was a sole care giver for five and half years. And six weeks later, I was diagnosed after burying him so it was hard coming home to nobody. So, that, that I found hard.”</td>
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<td>“I think the main one is having to deal with it on my own. There was nobody to help me. ‘Cause I live on my own and uh, my family is not with me. There was really nobody I can actually rely on.”</td>
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<td>53. Failed to remember the questions to ask</td>
<td>“It was I often couldn’t remember what questions to ask the doctor, I would remember them after getting back home.”</td>
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<td>Could not remember what questions to ask health care professionals</td>
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<td>54. Family conflict</td>
<td>“So the stress of being tired would make me grumpy and moody and all that, so it caused a lot of...a lot of, uh...just the arguments in the household, let me say, because I was moody.”</td>
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<td>Arguments, tension, and disagreements with others in one's family</td>
<td>“I think her, her way of dealing with it, she took the anger out on me.”</td>
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<td>55. Family failed to fully convey medical information</td>
<td>“…sometimes the children would tell me what was said…didn’t tell me completely, without care...because of my language...sometimes for example, many aspects when they couldn’t tell me properly then they wouldn’t tell me [Translator’s note: or can be translated as “when there’s bad news, they won’t tell me.”].”</td>
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<td>Family members may not fully translate and relay all the medical information given by health care professionals</td>
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<td>56. Fate or destiny</td>
<td>“Because I felt that all of this was, this was predestined by fate. You just should get this disease; you couldn’t even escape it.”</td>
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<td>Event occurred due to fate or destiny</td>
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<td>57. Fear of the unknown</td>
<td>“…the main source of stress would be dealing with the unknown.”</td>
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<td>Fear of the unknown</td>
<td>“The psychological part of not knowing ’cause you worry about things ’cause you don’t know.”</td>
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| 58. Feeling abandoned by health care professionals | • “...they didn’t seem to know what was going on and they didn’t really seem to want to try and find out what was going on. And so you were left feeling very isolated and very um like if I don’t deal with this nobody’s going to. You’re sort of thinking, I shouldn’t be the one to have to deal with this. There should be other people who know more who should be helping me deal with this.”  
• “Yeah, it was almost like we were sent home and didn’t know what to expect. And couldn’t seem to get anyone to communicate what that should be...It was kinda like I was thrown to the wolves and deal with it myself.” |
| 59. Feeling different from normal | • “It’s just reminding me that I’m not normal, you know, that again it’s I can’t…I can’t go for very long without needing to either put some water in or some gel in, something you know to…so it’s reminding me frequently.”  
• “…the effects on your um, self-confidence...”  
• “...simply because uh, throughout my life I was extremely uh, energetic. Hyper-energetic. And I’m not used to, I, I’ve never been used to, fatigue...”  
• “Because I didn’t feel myself. If I’m used to a certain level of energy and it isn’t there...”  
• “And because of the illness, and the, the I guess the by-products of uh, uh...the therapies, you know that whole sense of normalcy of who you are and what you are and what you can do and what you will do and what you can promise to do and- is just completely gone.” |
| 60. Feeling isolated or lonely | • “I feel that I’m alone. I live by myself and I have no, uh, close, nearby family, so it’s just kind of loneliness more than anything else.”  
• “I just felt that I was alone in the world with cancer.”  
• “…the times when you’re in a group and people will be talking, they don’t talk to you, they talk kind of around you and they talk over your head and so then you feel left out in a conversation and, and just kind of ignored...”  
• “…feeling alienated.”  
• “Everyone wants to feel, welcomed and if people don’t want to be around you, then that would be stressful to me.”  
• “…it would mean that I had cut off myself from God. That and being cut off from family, that would be my, yup, cutting myself off.” |
<p>| 61. Feeling sick | • “I guess ’cause you’re just feeling so lousy, really. Really no- I’m nauseated and, no energy. And always cold. I mean I’m still cold. Very cold and just, I would think that’s, the reason really.” |</p>
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<td>63. Financial stresses</td>
<td>“I’m just getting back on my feet financially. My God! Do I have to get another year off work? Am I going to lose my house?”</td>
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<td>“Because, say borrowing money, say your brothers and sisters’, so you must pay back, right? So, if you couldn’t find a job, what would you do? You only rely on your husband to pay it back, that stress would be too substantial.”</td>
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<td>“I had just arrived in Canada, almost two years by then. At that time, my English has also improved. I also, was preparing to get training [sic] for something, such as getting a license [sic]. So that I could find a good job here. So, just so happens at this time, suddenly got ill, this disease, the disease is a kind of cancer. Such a serious disease, it was not a common disease. So, I just thought...si, that, having been here for these two years, mainly I was that, I was, relying on my studies, improving. And my wife just took a labour [sic] job. Now I can’t, now she is carrying this heavy load.”</td>
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<td>64. Forced to confront that I have cancer</td>
<td>“I still had a fantasy that I didn’t have cancer. Later, that is, after the surgery, I didn’t dispel this fantasy until he told me the test results.”</td>
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<td>“...because it meant there was cancer and uh, I was going to have to embark on treatment, uh, I’d rather be healthy and not have cancer and not have myself being cut open.”</td>
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<td>65. Functional loss</td>
<td>“...knowing that I wouldn’t be functioning, functioning the same way I functioned in the past. I will always have a disability, no matter, there’s no correcting it. I’m always going to have a disability from now on.”</td>
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<td>“I think it would be almost the same as being, you know, paraplegic, where I, I just couldn’t do what I had always been able to do.”</td>
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<td>66. Having a rare cancer</td>
<td>“I think it was because with my type of cancer, not a lot of people knew what it was about. Like with breast cancer or any other type of cancer, it’s pretty common. But with mine, it was kind of hard to describe that there was anything going on.”</td>
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<td>67. High risk procedure</td>
<td>“And also, one of the surgeries I had was extremely risky because it was on my aorta. So it was very, the, the, the risk of dying during surgery was very high so I had to face that at the same time.”</td>
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| **68. Hindrance on social interaction or intimacy**  
Social interactions or intimacy are hindered due to illness and/or treatment | • “I now don’t eat together with friends and coworkers. That is because of dry throat, would…choke, would spray out immediately that kind of stuff. It is very difficult to sit down and eat with others, chatting while eating, became, this was very substantial stress.”  
• “I was working and I couldn’t work for a while and I missed that I like being with people.” (Note: the stressful thing here is that the participant is missing out on the socializing aspect at work)  
• “Yeah, like currently there’s yeah there’s a chance, there’s a relationship possibly and I, I sort of don’t know how to um…it’s hard to explain. The new dating thing right now -the fact I’ve been going out and say anything so. Person’s probably wondering why I’m not available, ‘cause all of a sudden I’m not available period so.”  
• “Um, just not being able to stay up sometimes, and to stay out with your friends, I would find that I would get really tired and want to leave and not hang out with them and just feeling tired um. Feeling tired at work. I would be working with the children and would just feel tired and not wanting to move around with them.” |
| **69. Inaccurate beliefs of cancer or treatment**  
Others hold inaccurate beliefs or are ignorant about cancer and/or treatment (including misunderstandings as a result of inaccurate beliefs about cancer) | • “…bothered me a lot that they started to ignore me like cancer was catchy.”  
• “…some people think it’s going to react like a switch and fix it you know but, it-it’s they-they need to explain that it will take time and it’s going to take some uh, energy and fight on your part…”  
• “…they think of tumour as a weakness…”  
• “…a client of mine when she first found out and I still don’t forget it, she said ‘oh, don’t worry it’s like uh, having cancer nowadays is like getting the flu.’ She doesn’t know w-you know my outcome. How could you say that? The flu? Cancer’s cancer.”  
• “Most people don’t get it. Um, the average guy on the street doesn’t really know anything about cancer. They, if they hear somebody’s got cancer, they just think oh that person’s had it, you know, they’re going to die. Um, they’re, they’re not used to the more recent developments where a lot of people have cancer and they’re around years later…and they’re around years later. A lot of people just don’t want to know about cancer.”  
• “…you know what [his name] we can’t count on you because you know we know you ha-you know have cancer...” |
| **70. Increased vulnerability to develop cancer**  
Feeling an increased vulnerability to development of cancer | • “I probably, more than the general public, have a higher chance of cancer coming back, having had it once already.”  
• “With the treatments for cancer, the scary part is, each treatment of cancer has a cancer development of its own. The treatment itself eventually will give you another type of cancer.” |
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<td><strong>71. Inhibited to voice demands on health care professionals</strong>&lt;br&gt;Patient feels constrained from posting requests to or challenging health care professionals</td>
<td>• “...having to ask for something, having to demand or uh, ask, well, it’s just asking something from what I understand to be an overburdened system.”</td>
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<td><strong>72. Instrumental burden on family and friends</strong>&lt;br&gt;Adding instrumental stresses or demands on family and friends due to illness and/or treatment</td>
<td>• “...you put a burden on other people, you know, or I put a lot of responsibility on my daughter for doing things...”&lt;br&gt;• “I felt bad that people were having to do things for me that I wasn’t able to do myself.”&lt;br&gt;• “The most inconvenient aspect was that the children and I, go for chemotherapy, treatment. It is the most, the biggest...my heart was, that is this disrupted the children from going to work, going to school like so.”&lt;br&gt;• “...my husband is home with the dog alone and he’d have to continue doing things without me type thing. And those things bothered me, because he’s older than I am and ah, and that that was my -really the only thing that bothered me – was leaving things to somebody else to do for me.”</td>
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<td><strong>73. Insufficient fluency in the English language</strong>&lt;br&gt;Patient has difficulty with the English language</td>
<td>• “It would be very distressful or very stressful for me to- have gone through this with a language barrier, for example.”&lt;br&gt;• “...the problem of language prevented me to speak to my professional doctor(s), there’s not much you could talk about.”</td>
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<td><strong>74. Insufficient information</strong>&lt;br&gt;Patient lacks information e.g., inadequate information given by health care professionals, or patient failed to absorb information despite sufficient information was provided</td>
<td>• “I didn’t feel prepared enough. For the whole uh, recovery stage of the whole process. I-I felt like I wasn’t um, given enough information or enough education. As to properly prepare to recover.”&lt;br&gt;• “...there’s only so much they’re going to tell you about your treatment, whatever kind of cancer you have. They only tell you so much in the beginning um, because they don’t want to stress you out about the incredibly long road you have to go on.”&lt;br&gt;• “It would be like dealing with the situation in a vacuum. It would be like having, not having any input at all about what’s wrong with you if you couldn’t understand.”&lt;br&gt;• “I was neglected to be told some information, so I didn’t find out until after the fact.”</td>
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| 75. Insufficient or conflicting information to make treatment decisions | • “...it was up to me now, I couldn’t again, get any more information. Say look, ‘Here’s what you gotta do.’ It was more like, ‘Here’re you options.’ I felt that. ‘Ok, what should I do?’…”  
• “...are you informed enough, uh, other options?”  
• “...because if both said do it, it wouldn’t have been a stressful decision but because one’s saying well, its up to you, you know, um, what risks you want to take, and you know that type of attitude. And the other one was like no I would recommend it. It was sort of tough to [mumble] which doctor do you listen to.”  
• “...having to make decisions that I know nothing about...” |
| 76. Insufficient or ineffective communication with health care professionals | • “Because there were some things that I possibly err…we couldn’t communicate well. That is, there were sometimes I didn’t quite understand what they were saying, they didn’t understand what I was saying.”  
• “You have to explain that to me in a way that I understand it ‘cause I don’t get that.”  
• “...unless I couldn’t get an answer, I would ask when I don’t understand and then if I didn’t get an answer then I would be upset.”  
• “Sometimes you don’t feel like the doctors are listening or giving you enough answers to your questions or answering it the way you want to hear it I guess.”  
• “...when it came to sign papers for my surgery, I was like, ‘oh, ok, what am I doing?’ like, I didn’t even know what was happening. I wasn’t, it wasn’t explained to me, I just, ‘Oh, just sign here, you’re going to have surgery on this date at this hospital and this is where you go,’ and I’m like, ‘Oh, ok, so we’re going to get rid of it, great.’ But there was no in-depth explaining that, ‘We’re only taking the right side of your thyroid, we’re not taking the whole thyroid...’”  
• “Clarity, I’d say. Um, because you know the-doctors when they talk, they talk in terminology that you don’t necessarily use. Or know what their talk-know what they mean. And uh, so I’d always ask, ‘Well what, what is thymus?’ ‘Well that means you can’t open your mouth.’ ‘Well then say that.’ You know?” |
| 77. Is the doctor minimizing the seriousness of condition? | • “…scared that the doctor would tell me…’It is nothing, it is nothing.’…you would think to yourself, ‘Is it actually very serious?’”  
• “…the doctor’s answer [sic] was, did he give you the whole truth [sic]? Or only answered you with a part of the truth [sic]. Should be that won’t tell, not telling you all of the truth.” |
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<td>78. Lack of (or insufficient) expected support and empathy</td>
<td>“Err…actually, it’s the fact that my family didn’t think about me. However, if this happens to me, if I feel that my family is treating me coldly, it would cause me the greatest impact.”</td>
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<td>Did not receive expected and/or sufficient emotional support and empathy from or feel abandoned by family and/or friends (or fear of it)</td>
<td>“I think the stressful part was uh, the not sharing because umm stress comes out in different ways and sometimes it’s a negative way for some people. Umm you know, and some people just ignore it and don’t help at all and then, then you feel neglected, you know. Umm other people you know need a kick in the butt to get them going again you know, and they’re afraid to hurt you or, or do anything wrong so they just ignore it, you know. So both ways they’re not helping.”</td>
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<td>“…what stresses you out is they can’t put themselves in your shoes and understand how difficult it is for you to communicate…”</td>
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<td>“I think probably just hurtful, you know, because people that you think were your friends or even they are your friends, just don’t know what to say or afraid to be around or, you, it does stress you out because you need them at that time.”</td>
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<td>“Because I feel, if somebody, if I’m sick and people are shying away from me, I feel hurt because I, I don’t understand why would people do that when you’re sick. They should be more for you, not against you.”</td>
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<td>“…like I told you earlier, like my mom had fallen apart you know and so I sort of, you know, I just felt like okay, you know, that person is not a source of support for me...”</td>
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<td>“I was surprised, I was surprised that there was so little support and when things needed to be done, really heavy duty things, they did not supply that and I was just surprised.”</td>
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<td>79. Lack of coordination within system</td>
<td>“That is, I was bounce around between hospitals [sic] to see doctors [sic]. Got sent around. So…and the most importantly was, my attending doctor, the oral surgeon [sic] who my dentist refer [sic] me first to [sic]. That surgeon [sic], I wasn’t sure if it’s his secretary’s problem or his own problem. So, he refer [sic] me to another hospital [sic]. It turned out that I waited, I kept waiting, he hasn’t refer [sic] me. He said he has made a referral [sic]. But, I actually made a call, call [sic] to that, that other oncologist [sic]. He said that he didn’t receive any referral [sic], like that.”</td>
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<td>Health care services were poorly coordinated, or patients get inconsistent messages from different elements of the system</td>
<td>“I think the main stress was just, you know, one doctor saying something and another doctor saying something and there was sort of conflict.”</td>
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<td>80. Lack of energy</td>
<td>“…the stress was mainly because of myself, not, weakness, was weaker, weaker...”</td>
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<td>Low strength or stamina</td>
<td>“And you just have no energy.”</td>
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<td>“Fatigue. Fatigue. Fatigue. I’m tired, tired, tired. So I just didn’t have the energy to do what I wanted to do.”</td>
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| 81. Lack of peer support               | • “...because nobody else has experienced it, or nobody else understands it, that um, that becomes very stressful, because you do feel, like you’re, you’re by yourself in dealing with it.”
|                                        | • “...probably having no one to relate to or um, not knowing anyone else that went through it...” |
| 82. Lack of practical assistance       | • “Because, I…I live by myself. So…my family is not in Canada, so that’s why I was thinking, ‘I am sick, I am alone, how will I take care [sic] of myself.’” (Note: “take care” often refers to practical day-to-day aspect of life in Chinese context)
|                                        | • “...you cannot always rely on people. The-they can’t stand by at your side 24 hours a day. So always, you’d find that, if it keeps going like this, what then?”
|                                        | • “...how would I ever take care of myself? You know, going through the radiation is uh…I had to have help. I just…there’s no way I could do it on my own after the first week.” |
| 83. Learning to live with cancer       | • “...the hardest part was not going through the treatment and stuff, it was trying to get back to life after...”
|                                        | • “...learning to live with the diagnosis that I was given. Just- Yeah, just…well, it’s for the rest of my life it’s there. And just have to learn to accept it.” |
| 84. Less able to participate in valued activities | • “Just not being able to do what I want to do. Being constricted and limited.” (Note: want to do; not “need” to do => valued activities versus responsibilities)
|                                        | • “I find that ah, like I love to walk and I can’t walk the distances I used to without getting tired.”
<p>|                                        | • “Yeah, or even if I lost even an opportunity. Because I look at my age and say I’ve only got realistically maybe 20 years so that’s 20 hunts sort of thing is the way to look at it. And to me, it’s too precious to give up so you do what you have to do.” |</p>
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| **85. Life on hold**                   | • “...you’ve kind of had to put your life on hold because of the cancer...”  
  Unable to plan for future or move on in life  
  • “...originally my plan [sic] was to get married. So but I got this disease so I have to...delay, delay [sic].”  
  • “...if someone said, ‘Would you like to have lunch next Friday,’ I would say no, because I don’t know how I’m going to feel. And I found it stressful dealing with, people who wanted to do things for me but not being able to go along with it. So that’s what I found stressful, and, and plan ahead.”  
  • “...the frustration of not being able to make a decision for me because that has not been one of my difficulties in life. Not being able to make a decision, yeah. Well it says here make a de- makes it difficult to do things, that means do things, you make a decision to do it. So that means you’re, in my mind anyhow, that you’re indecisive and that’s not the way I’ve been.” (Note: inability to make decision resulting in feeling stuck, consistent with life on hold)  
  • “...since the beginning of my cancer, uh, through the treatment, through everything, there’s always been something else come along that’s been related to either the cancer or to the treatment, uh that has held me in a position, uh where I can’t advance any farther...” |
| **86. Little time to adapt or respond** | • “Because it was, it all happened very quickly. It was, um, sort of had 2 weeks to get used to that idea, before the surgery.” |
| **87. Losing chance to see kids grow up** | • “...not being able to be with them and watch my kids grow up would, would have been a huge loss for me.” |
|                                            |             |
|                                            |             |
Stressor appraisal name and description | Exemplar(s)
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88. **Losing control**
Feeling one cannot influence the course of events and feeling helpless; "pang-huang" (feeling associated with trying to escape from inescapable threat); "wu-nai" (feeling of resignation associated with recognizing one cannot escape from an inescapable threat)
- “I felt very 徬徨 (pang-huang) [Translator’s note: one feels discomposed because he doesn’t know what to do and is indecisive.]. That is what I’d felt. Because this year is not the first time I had cancer [sic]. In the past…I had it when I was in my teens. Around 18. At the time, I never thought that I would die, very calm [sic]. That is it was nothing. This time the feeling was very different. So I felt that I [mumble] I was useless…that’s why [mumble] courage to [mumble]. [Sounds very upset]"
- “Because I, I always take care of [sic] my own business [sic]. That is I take care [sic] of myself, take care [sic] of a lot of things. So that’s why, I felt, ‘Oh! I am sick, a lot of things, I can’t do myself. So, so also mmm…have, have to rely on others to do them.’ Have to, so I thought handing, handing, handing over to other people, to help me do things, felt that it was a very big…problem. Sometimes, I discovered that it was really, they were done not in the way I had in mind, they didn’t really understand what I wanted done or they helped me by 自作主張 (zih-zuo-jhu-jhang) [Translator’s note: a Cantonese phrase meaning acting in accordance to their own will.]. Right, that’s why sometimes it is really…that is I think it was really, really 無奈 (wu-nai) [Translator’s note: a Cantonese slang meaning not have a choice].”
- “The only thing that stresses me with cancer is if I was to have it to a point where I’m just slowly degrading and I couldn’t do nothing about it. I’d find that awful. That’d be a terrible way to go.”
- “I think that’s because I didn’t know quite what was going on. I wa…I felt separated from it, like it felt like my wife and my parents were the ones taking care of it with the doctors, and I was sort of just, over here and I, I wasn’t sort of, involved, I like being involved li…and stuff like that and I didn’t feel that and I think that’s, that might be one of the things.”
- “I couldn’t have it any…any more children, so I found that stressful because, it wasn’t really my choice not to have any more, it was kinda just handed to me that way…”

89. **Losing independence**
Loss of (or threat of losing) independence (including emotional independence) due to reliance on others for care
- “Because I, I always take care of [sic] my own business [sic]. That is I take care [sic] of myself, take care [sic] of a lot of things. So that’s why, I felt, ‘Oh! I am sick, a lot of things, I can’t do myself. So, so also mmm…have, have to rely on others to do them.’ Have to, so I thought handing, handing, handing, handing over to other people, to help me do things, felt that it was a very big….problem.”
- “I guess it was just stressful because before I lived on my own, so I was very independent, so it took a while to get used to not being able to do just regular everyday things like getting groceries and doing housework, having to depend on other people.”
- “I felt very emotionally dependent.”
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| **90. Losing opportunities to fulfill role or responsibilities**<br>Chances to fulfill roles or responsibilities in life have decreased (including threat of). Role refers to socially expected behaviour patterns usually determined by an individual’s position in society | • “...just my reliability to other people you know, whether it’s a job or family. Umm you know you-you have to stop and think you know you’re making this commitment to these people, whether it’s family or-or to a job, and then you think like what if I can’t fulfill it...”
• “Because I felt guilty about not doing the things I was supposed to be doing, you know. Housework, cleaning, vacuuming, you know. I only done, I’ve done laundry and I’ve done one meal a day, and that would be my life, besides laying on the couch.”
• “Yes, they would be worrying about me and I would be afraid that if that was the case then they wouldn’t necessarily come to me. They wouldn’t come to me and you know, share whatever their problems are, if they knew, they would be worried that they would upset me further...” (Note: Others staying away led to patient cannot fulfill usual role as problem-solver) |
| **91. Losing time to spend with family**<br>Losing chances (or fear of) to spend time with family (including pets) | • “I wanted to be with my kids. I wanted to...my, my niece was around too. I wanted to be with my family.”
• “Mostly in bed so I have lost a lot of time with my kids. I have a, I have a 16 month old baby so I missed the entire first year of his life. So that’s very stressful for me like he didn’t even know who I was up until three months ago so that’s pretty hard...” |
| **92. Loss of meaning in life**<br>Loss of purpose or meaning in life (including will to live) | • “Because when you feel terrible all the time, and you know, in this case, is there any meaning... do you want to live or do you want to not live is the question.”
• “When there’s nobody around, you would that is, would think, ‘Why should I still be here? Better being dead!’ That is since no one is there to pay attention to you, at that time I would think like that.”
• “I think I would have given up. You know and that would uh...for me that was all-giving up is stressful...” |
| **93. Loss of relationships**<br>Family and/or friends temporarily or permanently leave the patient due to cancer (including threat of) | • “I lost a whole bunch of friends, uh, a whole bunch, whole bunch, several.”
• “...will my husband still love me for who I am even though I have scars?” |
| **94. Loss of self-esteem**<br>Loss or decrease of how one values oneself | • “I felt that I was very 失败 (shih-bai) [Translator’s note: a Cantonese term meaning loss and defeated]. ‘How come I had to, had to get this disease?!’”
• “I think I had a little bit of an extra burden with that because you sort of feel as if I should know the right answers. So it would even be harder for me because it would be, you know, not only am I not making the right decision personally but professionally I’m not making it. So it’s sort of a reflection not only on my personal competence but my professional competence. So it’s sort of uh, it’s a self-esteem kind of thing.” |
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<td><strong>95. Medication insufficient to relieve symptoms &amp; side effects</strong>&lt;br&gt;Unable to get relief from symptoms and/or side effects resulting from insufficient medication or intolerance to prescribed medication</td>
<td>• “Just because I was hypothyroid with this one, I guess this is regarding the thyroid cancer because they didn’t give me a medication that was strong enough, so I was tired all the time and that really frustrated me because I was a fairly active person and I like to go out and run around and play but I just couldn’t because I was too tired. I was at school, so I did my school stuff but I was just…I got so miserable ‘cause I was so tired all the time, so…it was stressful.”&lt;br&gt;• “…the simple fact that of having to deal with the pain and not getting any relief from it.”</td>
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<td><strong>96. Misdiagnosed</strong>&lt;br&gt;Patient’s condition was misdiagnosed, including receiving unnecessary treatment as a result</td>
<td>• “I was misdiagnosed for two and a half years and so naturally…naturally I probably would not had to have had radiation or the degree of surgery that I had, had I been properly looked after.”</td>
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<td><strong>97. More difficult to get things done despite the desire to do so</strong>&lt;br&gt;Increased difficulty in accomplishing tasks or activities due to disease and/or treatment; similar to Chinese phrase of li-bu-cong-sin (&quot;You don’t have the energy to do what you desired.&quot;)</td>
<td>• “…it just limited how much I can do in a day.”&lt;br&gt;• “I would be annoyed or frustrated or, you know, I couldn’t, for example, I was making a meal and normally what would take maybe half an hour or an hour to make it, it took me hours because I was almost sluggish, you know just moving a little bit more slowly, and I would sit down and you know I’d, I’d season the meat and then stick it back in the fridge and go and rest and then I’d get the potatoes, clean them, and then go sit down. So just getting through the day, regular day stuff was slower than usual.”</td>
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<td><strong>98. My body let me down</strong>&lt;br&gt;Disappointed that physical health and integrity were compromised to the point that one cannot perform as expected</td>
<td>• “…especially when you don’t feel sick anymore and you think okay I’m back to normal and I can do this and then you try to do it and you, you realize your body is saying, ‘No, we’re not back to normal yet.’”</td>
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<td><strong>99. Negative consequences of delay in diagnosis</strong>&lt;br&gt;Experienced negative consequences due to delay in diagnosis</td>
<td>• “…my other fear was because I left it for so long. I didn’t see the doctor for annual check-up for five years prior to that one check-up in 2006 so therefore I’m thinking, ‘I left it for so long. It could have gone through my whole body.’”&lt;br&gt;• “You know, it’s hard to…you only see the doctor, I only see the doctor about once a year. And my mother went once a year or every 6 months now. So you just wonder if it’s enough. Like enough check-ups.”</td>
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<td><strong>100. Negative consequences of delay in treatment</strong>&lt;br&gt;Experience (or possibility of) negative consequences due to delay in treatment</td>
<td>• “...if you’re waiting for surgery and you know you have a cancer growth that’s growing and could be spreading and you have to wait and you understand that there are people worse off but you still want to be first to get in there to get it off, to get it out of you.”&lt;br&gt;• “I guess realizing that I needed to get this taken care of immediately before it can progress to something more serious.”</td>
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<td><strong>101. Negative thinking</strong>&lt;br&gt;Worry about the possible negative illness and/or treatment consequences or engage in self-defeating thinking</td>
<td>• “...if you are going through, you know, treatment where you’re incapacitated, you’re already dealing with I might die and now I can’t do this, so you’re already entering you know ‘I’m gone’ type of uh emotion.”&lt;br&gt;(Note: “gone” often refers to deceased or death)&lt;br&gt;• “...the mind has a funny way of working when there’s lots of time in between what the next step is.”&lt;br&gt;• “Because it’s always in the background that something could go wrong. And when something untoward happens, one fears the worse.”&lt;br&gt;• “I was a concern to me, and uh many times if you go over something in your own head, without uh releasing it and expressing it to somebody, uh you can kind of feel that long anxiety.” (Note: Keeping all the thoughts to oneself builds up to anxious feelings)</td>
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<td><strong>102. No one to talk about illness</strong>&lt;br&gt;No one is available to talk to about illness experience</td>
<td>• “...having nobody to talk to. Obviously nobody to comfort them, nobody to be positive to...for them, you know and you can’t go through something like that by yourself.”</td>
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<td><strong>103. Obliged to get better</strong>&lt;br&gt;Feeling that one must do all that he/she can to get better due to others’ worries</td>
<td>• “...it’s a, kind of pressure that...you’ve go to do something. Or ya got to get better...”&lt;br&gt;• “...I couldn’t control their level of stress other than by getting healthy myself...”</td>
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<td><strong>104. Ongoing experience of side effects</strong>&lt;br&gt;Persistent experience of side effects</td>
<td>• “So I guess that’s when I sense that this doesn’t just end with the treatment, there’s a lot ahead in terms of having to cope with the results of your treatment, cope with the side effects of the treatment and then...so I think that stress obviously subsided with time, but then as the late radiation side effects in years then that sense of struggle obviously it came back, you know.”&lt;br&gt;• “I have dry throat because of the radiation and because of that I, I went through about 12 to 13 bottles of water a day. And because of that, I’m up all night peeing. So I’m either getting up to have a drink or getting up to go to the washroom so since, I’d say in the last 3 years, I don’t think I’ve had much more than an hour and a half of sleep straight without having to get up.”</td>
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| **105. Others being close-minded**     | • “…they may be experiencing it and they don’t want to hear from somebody that’s had it and is feeling better – and that kind of bothers me, where I think they- But most people are, want to talk about it and you know, that’s that. It’s as if they’re very umm, it’s- they, they want to not believe that they have it and they don’t want to talk about it because they know that you’re ok – and its kind of a a-a-feeling that they have. And until you find a way of talking to them you just don’t and that kind of bothers me because, like I-I have a friend who is having trouble with her lungs and she smokes, and she doesn’t want you to talk about not smoking but she will listen to go and see your doctor, you know, type thing.”  
  • “That means not being accepted.”  
  • “...to me people like that have themselves in a little bubble, in their own little world and umm it’s not the way it is you know. And they don’t want to deal with somebody else, their emotions or you know anything like that and it just makes me angry because it would make me angry because of thinking that ahh how can you be so closed…closed off to you know what’s happening.” |
| **106. Others feeling uncomfortable**  | • “…they’d be afraid that I’d be broken-hearted, not knowing how to comfort me.”  
  • “And I think part of it, to give people credit, they don’t know what to do. People don’t know how to respond, when they find out you have cancer, they don’t know what to do for you, they don’t know what to say, they don’t know what’s appropriate so they just avoid you like the plague. D’you know what I mean? So people don’t phone, people don’t send cards, people just, boom, d’you know what I mean?”  
  • “…it’s stressful being in a situation where other people don’t understand because you yourself understand so you just sort of feel awkward for them. Much in the same way as you feel awkward when you’re having a conversation with somebody and they just have no idea what’s taking place.” (Note: awkward social situations)  
  • “Their discomfort at it, their distress that we, that I would be makin’ them uncomfortable.” |
| **107. Others treat me differently**   | • “I guess just be stressful to have people who, at one time looked at you normally, have them treat you differently.”  
  • “…you haven’t changed in any way but then people will all of a sudden look at you differently.” |
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| **108. Overwhelmed by the situation**  | • “I’m trying to think about it. Well the feeling is like, ‘Oh God, I want to die, I can’t bear this.’”  
  The demands of the situation exceeds participant’s coping ability or resources  
  • “I mean I try not to lose hope and stay focused...” (Note: the issue is participant being unfocused)  
  • “...just becomes one of those dark holes that I don’t know how you get out of.”  
  • “It was inner stress more than anything. It was just me putting the stress on myself ‘cause every once in a while I’d, I’d go to bed and say I can’t, put my head under the pillow and say, ‘I can’t face this.’ Face the cancer, my whole life changing, and you know, things like that.”  
  • “I think ‘cause the mind is working overtime, you know. Like just tires you out, it wears you down.” |
| **109. Patient has ultimate responsibility to make the decision**  | • “Because it would be my decision and then whatever the consequences were it would be as a result of myself not the doctor...”  
  The patient is the one who has to make the final decision about treatment  
  • “…the doctors really couldn’t say one way or the other, yeah, their recommendation was to take it out, but, uh, I didn’t necessarily have to do that. You know so there’s really nobody there making those decisions for you, you have to come to those decisions on your own...” |
| **110. Patient’s personality incompatible with situation**  | • “I’m an engineer. I like to know how things work and I need to have a lot more information to have a….um, an educated decision, an educated advice from them. And that’s why I found that um I did not have enough information. They just tended to um brief, briefly go into some sort of detail. Well frankly, I need to have a lot more information to provide uh...provide comfort to myself. I have no problems of undergoing an operation, or medication, or treatment, whatever it might be as long as I know why we’re doing this. You know, I can’t accept just because you have to do it. I need to have the information well, these...these are proven test methods, this is uh, um, uh, the percentiles of, of success, or whatever it might be. But I need to have that type of uh data. And unfortunately I never received...”  
  Patient attributes stress to a mismatch between his/her personality (or needs) and demands presented by the situation  
  • “I’m impatient with people, very impatient. So, um, when, when you have people that I would be looking to -for some type of assistance, um, I would become impatient with their inability to fulfill my requirements. Or the, just or, the way they would speak. Okay, they would uh, ‘cause it’s awkward, it would be awkward for them. And um, I just find people um, they have a, a, an inability to speak succinctly and properly and-so I, I would be very, become I’m-impatient. So that would cause stress on, on my part.”  
  • “I’m predisposed to find everything a little bit stressful...” |
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<td><strong>111. People acting insensitively about patient’s cancer</strong>&lt;br&gt;People behaving insensitively (e.g., staring, asking pointed questions, and ignoring the fact that the patient has cancer)</td>
<td>• “That’s all I can say is they weren’t interested. They were just being bloody nosy.”&lt;br&gt;• “…people would totally ignore the fact that you had cancer and try to act normal.”&lt;br&gt;• “…everybody looks at me, when, when I talk. You know, kids around me, ‘Oh, what’s the matter, what’s the matter, what’s your matter.’ You know like if you tell one, they go around with their friends saying, ‘Oh, can we show our friends the hole in your neck?’ And then a lot of them say, ‘Oh that lady had her neck cut. Somebody chopped her neck.’”</td>
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<td><strong>112. Preoccupation with thoughts of cancer</strong>&lt;br&gt;Thoughts of cancer overtake one’s day (including concerns whether the preoccupation is normal)</td>
<td>• “There’s never a day go by you don’t think about it. I mean maybe not hourly but you think about it everyday.”&lt;br&gt;• “Because they cut nerves and even to this day, after years, still it’s like numb. My ear lobe is numb, my jaw, the side of my jaw, my mouth, it’s a little bit numb. And you like you always feel it when you’re lying down or something and you’re always thinking, so it always reminds you that you’ve got cancer, it’s always something that you cannot just put away.”</td>
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<td><strong>113. Preoccupation with treatment</strong>&lt;br&gt;Treatment demands take over thoughts and daily life</td>
<td>• “Every day I would have to…thinking about and dwelling on [the treatment]. I would come home today, tomorrow I would have to go out again …it would seem like that I don’t have a day of peace and quiet.”&lt;br&gt;• “…when I was going through the chemo and the radiation uh it was very stressful in a sense that I was, I was very lucky and I was able to have the Canadian Cancer Society drive me back and forth from home but quite often because of the way it was arrived at, I would be leaving the house at maybe 7 in the morning for an 11 o’clock appointment uh so I’d be getting here at the hospital around 8, quarter after 8, the appointment would be at 11, but then we had to sit and wait around for the driver and sometimes I wouldn’t be home until 5. So I’d waste a whole day sitting in the hospital…”</td>
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<td><strong>114. Pressure from others concerning work responsibilities</strong>&lt;br&gt;Pressure imposed by others to fulfill one’s obligations at work</td>
<td>• “…sometimes it’s not, uh, the sickness that you’ve got, it’s how you’re treated by your employer and your fellow workers. ‘Cause um, some companies they’ll just say, ‘Oh, well, you’ve got that, look after it, come back when it’s over.’ Other ones will say, ‘Well, can you work late Friday?’ You know, like, ‘You’ve got an appointment on Thursday, can you work Friday?’ So that would make more stress.”</td>
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<td><strong>115. Procedure too expensive</strong>&lt;br&gt;Medical procedures are very costly (including patient not being able to afford it)</td>
<td>• “…because of my loss of teeth. And um, knowing the fact that I probably won’t be able to have implants because it’s so costly.”</td>
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| 116. **Reassuring others or uncertain how to do so**  
Comforting or providing encouraging information to others about one’s health status (including being unable to or unsure how to do so) | • “I think most stressful because there was really nothing I could do to say to them to make them feel any more comfortable or any more at ease with things.”  
• “…having visitors come in and reacting, react in a caring way, but also they were upset and crying. So it’s not only was I looking after myself I felt, I had to now look after them…”  
• “I feel like I have to reassure other people that I’m ok.”  
• “…how to deal with my family, how to deal with everybody else who was freaking out around me.” |
| 117. **Recovery time longer than expected or desired**  
The length of time requires to recover from cancer, its treatment, and/or return to normal activities is longer than expected or desired | • “The recovery time. Yeah. I expected to be um more recovered than what I am. It’s taking a lot, a lot longer than I had realized that it would take.”  
• “I’ve been doing a lot of exercises and programs for it to strengthen the area, my neck, my upper body, to gain the weight back that I lost and so on. And I’ve been very, very seriously doing that and it’s working up to a degree and it’s working very well, I guess, but I guess I’m impatient because it can take you know several months.”  
• “…anxiety of not being able to return to work when I would’ve liked to. Um, I really would’ve liked to have gone back in about January and I’m not going back until, well, a couple of weeks from now so, I’ve had basically nine months of thinking about that so, that’s caused some stress.” |
| 118. **Re-exposure to previously experienced cancer stressors or situations**  
Encountering past cancer-related stressors, (including direct experience, memories, or threat of re-exposure) | • “Because I really don’t want to go through any hospital treatment or any operations. Yeah, I don’t want a repeat of that.”  
• “…every morning that coffee reminds me of like how I’m a little bit different.”  
• “Just the memories of going through treatment and stuff, when I had my hair loss, chemo and radiation and all that before. So it’s just stressed because I kind of relive it.” |
| 119. **Re-telling of cancer experience**  
Repeated telling of his/her cancer experience | • “Didn’t want to tell, didn’t want to see, also didn’t want to hear others that is, that is other people would for sure ask you, but keep repeating, repeating [sic] basically didn’t want to tell it again…”  
• “They’re always asking you. Every time you see somebody new, you’re re-reading the script again and you have to do that ten times a day. It’s a repeated story for you, but a new story for somebody else. That’s what you get tired of.” |
| 120. **Self-blame**  
Blaming oneself for getting this disease | • “…because I feel that my smoking contributed to that…to a certain degree. And even though I quit 20 years ago, that I would have some- there would also be a bit of guilt because I somewhat contributed to my disease.” |
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| **121. Self-imposed limitations**
Feeling compelled to avoid situations in which one can no longer perform effectively | • “I’m afraid to go on the highway now because my surgery I, because I’m not able to talk in case I get in an accident or something. I’m a little paranoid to go on the highway. That’s one of my biggest problems.” |
| **122. Self-pity**
Feeling sorry for oneself | • “Feeling sorry for myself basically.” |
| **123. Self-procured information is threatening**
Information about one’s disease acquired on the Internet or by other means is threatening | • “…probably just reading up on the particular uh, illness that you have and i-not automatically go to the most acute case and wonder, wonder if it’s at all possible that it could happen to you.” |
| **124. Side effects**
Physical suffering due to pain and/or side effects | • “…not looking forward to the pain…”
• “The main cause, this would’ve been right after the surgery, after about 4 days of the pain. The frustration at not…at still having the pain and not getting past it yet which made me angry.”
• “…but actually dying part wasn’t that stressful. Um, more suffering before dying.”
• “Actually when you are weak and tired, you, at that time your…it actually affects your willpower, your thoughts. Some people, some people’s…thoughts are very clear. Mine, mine, mine got worse.”
• “…in fact during my post-operative phase, I was very, very nauseated, um either from medication or from the tube feed, and I kept throwing up, and throwing up, and throwing up. And in fact one night I felt I was gonna throw up my trache actually.”
• “It was just the pain and discomfort.”
• “…because around that going to the, back to the hospital after I’d had my, my surgery, I was home then the stitches tore in my mouth that was very stressful for me.” |
| **125. Stigma**
Others construe the person as marked or deviant, and/or evaluate him/her negatively due to cancer, which may result in being ostracized (including threat of stigma) | • “Mainly…about work. That is, would other people think that I’ve gotten…weaker? Also perhaps…don’t see you as capable? Or, that is, mainly it’s these types of problems.”
• “Not being regarded as a normal person by people.”
• “…that is seeing you is like that is, that is equal to HIV [sic], those people, ‘Wow! You have AIDS! [sic]’ That is it’d be like so, that is same thing [sic].”
• “And then knowing the word ‘cancer.’ Like that that itself is a big you know, big black mark on your forehead sort of thing, I dunno.” |
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<th>126.</th>
<th>Stress &amp; uncertainty concerning additional health crisis or issues</th>
<th>• “Ah, because now I have diabetes to deal with, it’s stressful. Ah again, um having weight on my body and I’m finding it a little bit hard to deal with.”</th>
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<td>Stresses and uncertainty resulted from additional illnesses experienced (including mental health issues) during cancer experience</td>
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<td>127.</td>
<td>Subjugating personal needs for group priority</td>
<td>• “…you feel like you have to take care of them, but you’re the one that’s sick and so that might cause a little bit of stress or resentment.”</td>
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<td>Patient suppressed his/her needs, thoughts, and feelings to address others’ needs</td>
<td>• “Well, I think I always had to be cheery and up-beat and everything, for everybody else around me, like my parents and family, which was you know, exhausting, when inside that’s not really what I felt. It was like, putting on a show almost. So, you know, I wasn’t being my authentic self you know, you couldn’t say, I was so worried about what everybody else was feeling that I, I kind of um, submerged what I was feeling. I wasn’t truthful to myself very often.”</td>
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<td>• “…everybody just wanted me to be happy all the time, so, that’s where most of my stress came from, pleasing everybody else.”</td>
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<td>128.</td>
<td>Symbolic threat of cancer</td>
<td>• “I guess the word cancer scares them so they just didn’t acknowledge it…”</td>
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<td>The word or concept of cancer automatically elicits fear, doom, or concept of a death sentence</td>
<td>• “…most people are afraid of the word. They’re afraid of all the connotations that go along with it…”</td>
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<td>• “Oh just living with uh that ‘C’ word.”</td>
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<td>129.</td>
<td>Symptoms or side effects unexpected or worse than expected</td>
<td>• “…you actually expected to be very tired, would have a bit of…weakness, but…when it actually arrived, you felt, ‘Oh my god, will I, will I die?’”</td>
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<td>Symptoms and/or treatment side effects were unexpected or more severe than anticipated</td>
<td>• “I knew how tired I was going to be but I didn’t think it was going to be this bad.”</td>
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<td>130.</td>
<td>Taking care in telling others</td>
<td>• “…just trying to figure out what kind of an answer to give them, because you vary your answer, you vary answer from everything where you say you know you’re going to die to the casual acquaintance or you just say everything’s fine, so you have to try and figure out what kind of an answer is most appropriate to give.”</td>
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<td>Need to consider how best to tell someone about one’s illness, including the decision that there is no satisfactory way to do so</td>
<td>• “I was very concerned with what to tell him. I didn’t want to lie or deceive him but yet I had to give him hope.”</td>
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<td>• “I guess communication, with uh…uh…like particularly with…with my mother. I don’t…I don’t want to, uh, give her too much information.”</td>
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<td><strong>131. Threat of unable to care for loved ones if one dies</strong>&lt;br&gt;Feeling vulnerable to not being available to care for family and loved ones (Note: When response emphasizes how family will manage in the absence of the deceased loved one, assign it to “Concerns how family would cope after one dies”. When response emphasizes the concern that one will be unable to provide care for loved ones, assign to “Threat of unable to care for loved ones if one dies”)&lt;br&gt;“…because I still need to look after my little kids…”&lt;br&gt;“…you don’t want to leave your wife behind and you want to look after her…”&lt;br&gt;“I think it’s more because of my mom like I’m taking care of her. And I don’t want to go before she does, you know, she’s 76, she’s diabetic and she’s got heart problems and she’s on her own. So like I’m just sort of think well, you know, “I still have to take care of my mom, I can’t be sick, I can’t be” you know.”</td>
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<td><strong>132. Threat of cancer being incurable</strong>&lt;br&gt;Feel vulnerable that cancer may not be curable&lt;br&gt;“…you worry about the worst case scenario, having uh, stage 4 cancer and there’s nothing they can do…”</td>
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<td><strong>133. Threat of cancer getting worse</strong>&lt;br&gt;Feeling vulnerable to the possibility of new cancer, recurrence, metastasis, and/or health deterioration (Note: When “threat” is mentioned, the particular excerpt should be coded here)&lt;br&gt;“So I went to umm…I went to the doctor for an annual check-up, I misunderstood one word he said, and an answer to what I talked to him about some problem I had, and he said, ‘Well, you’re weights up,’ and I thought he said, ‘Well, you’re whites are up,’ and I freaked. I mean I didn’t scream and yell, but I was like, ‘What?!’ [loud voice], you know, and my blood pressure went up, my heart started pounding and it was a freaky moment…”&lt;br&gt;“…now I knew that I didn’t have to have radiation, but [doctor’s name] said you know, you have you know a strong rate of recurrence within two years. So was I going to have a recurrence?”&lt;br&gt;“Well, it would be, is the cancer spreading? How fast is the cancer spreading?”</td>
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<td><strong>134. Threat of death</strong>&lt;br&gt;Feeling vulnerable about the possibility of impending death&lt;br&gt;“…am I cashing in my chips now? Uh, am I going to die?”&lt;br&gt;“The time frame [sic], that is, a person’s time [sic], a person’s life [sic], the time frame [sic], how much is there? If this is question.”&lt;br&gt;“…my life was threatened.”&lt;br&gt;“I’m gonna die…”&lt;br&gt;“…the other thing that was stressful was knowing the percentage that-I mean I, I can tell you, I can’t tell you the number of times that forty percent just kept flashing, flashing.”</td>
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| 135. Threat of dependent’s instrumental needs not being taken care of  
The instrumental needs of the dependents (human or pets) may not be met (including after his/her death) | • “…who’s gonna look after this baby if whatever is gonna happen to me on this journey.”  
• “And it’s uh, see, if I didn’t have kids then I don’t think I would worry that much about it. And just making sure if I’m not here they’ve got the funds for university and that my life insurance pays off enough and things don’t change that much for them.”  
• “…who’s going to look after my family, what’s my wife doing in Collingwood when I’m in Toronto having the treatments? How does that affect her? How does it affect the rest of my family…” |
| 136. Threat of disability  
Feeling vulnerable to possible disability or incapacitation | • “How and what the outcome, yes. Yeah. What the outcome would be. Will I be uh, disabled? Will I be incapacitated? Will my brain still be functioning? Thyroid’s pretty close to the brain, you know. That sort of thing.”  
• “I guess I didn’t want to be an invalid.” |
| 137. Threat of disfigurement  
Feeling vulnerable to physical disfigurement that would affect appearance | • “…it made me feel like I’m gonna have a scar, I’m gonna look a little bit different.”  
• “…only the fear of uh I had a fear of post-operative what would I be looking like, it’s a very disfiguring surgery. So how would I be looking?” |
| 138. Threat of having recurrence that is more difficult to treat  
Feeling vulnerable to having a recurrence that will be more difficult to treat or for which fewer treatments options exist | • “…on the occasions I’d think about it, how it would progress, you worry that… would be stressful because you can’t have anymore radiation so what would they do, so the idea of what would happen next if it did recur.”  
• “Recurring means to having to face an even more in-depth treatment and more serious suffering/pain and to face death.” |
| 139. Threat of lost opportunities will never return  
Feeling vulnerable that the lost opportunities will be gone forever; “Missing the boat” | • “The opportunity may not always come back.”  
• “…being in a, in a situation that won’t allow me to work, having to completely reinvent myself after a 45-year career, that’s scary stuff. You’re not reinventing yourself at 55-56 years old, not in my business you’re not. You know if you’re over 30, you’re old, in my business, you’re not. So, that would be the greater stress for me, is…is my career over?” |
| 140. Threat of unremitting or additional suffering  
Feeling vulnerable to the possibility of prolonged or additional suffering | • “You know I don’t want to live the rest of my life suffering from cancer…” |
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| 141. Threat to health and safety of loved ones  
Health and safety of family and loved ones are in danger | “And I was also concerned about their health that you know I wouldn’t want them to have to go through it. You know because I’m, I’m your sister so you know, I was worried about well you know what if they get cancer as well, what if they get a similar thing because of uh you know relation…genetics.”  
“When I went through the uh, radioactive iodine treatment. You know, the, the isolation and that kind of thing. The, the, you know, questions surrounding that, and making sure I don’t contaminate others and that kind of thing.” |
| 142. Threatening side effects or symptoms  
Occurrence of threatening side effects and/or cancer symptoms (or the threat of), or interpretation of side effect to indicate worsening of condition | “So the cause of the stress is that every little pain that I feel now, I always think it’s cancer.”  
“…because I was thinking something else was going wrong, and it was actu…an actual side effect of having the radiation.” |
| 143. Treatment-related adverse events  
Unexpected health-threatening events occur during course of treatment (or fear of) | “For example that time after I got my stomach tube, returned home for a week. A few days the medicine, that is two, three days so err used…But then once I used it, my stomach hurt a lot like so err…couldn’t handle it, so I returned immediately to the hospital…that is my wife called the hospital to ask. So, so after I returned to the hospital. That is had to…err pull it back out. That is he did it wrong, that is it was not deep enough, it turned out…water got into the abdominal cavity. That’s why very, that is turned out…very painful, very miserable.”  
“’Cause I had a couple cases where um I was allergic to the medication and I was in a lot of pain so. I was worried that, ‘Am I going to be able to see the doctor in time to get the you know?’” |
| 144. Trying to maintain normal life  
Attempts to carry out normal activities despite limitations imposed by illness | “…the surgery and the uh, um, the treatment and having to deal with work at the same time.”  
“…a lot of things continued at home. That is, everything wouldn’t stop just because you have cancer, that is, to let you do your own things. That is, you have to keep doing everything, and you have to handle [sic] yourself. I felt stress there.” |
| 145. Unable to contribute  
He/she cannot contribute to others; feeling useless | “…felt like mmm…I was very useless.”  
“I’m not giving to society…”  
“I feel guilty if I can’t pull my own weight.” |
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| 146. **Unable to live one’s life to its fullest** | • “…you’ll become so incapacitated that, uh, your life, the quality of life that you’re used to, will not be there anymore.”
• “Because the mere fact um if my life was going to be over, I would have a lot of regrets of how I lived it or maybe should I have lived it differently. And it’s like wow I missed this or I should have done that, or I wasn’t appreciated enough for this or I didn’t treat that person the way I should have. So you’d have a lot of almost guilt or remorse of how you lived your life.”
• “What if I, you know [sic], there are many things I haven’t done, a lot of things I haven’t seen, a lot of things I haven’t said.”
• “Maybe that I hadn’t done enough in my life. Maybe that I hadn’t, fulfilled enough in my life.”
• “I just enjoyed my life and…Bad and good. It’s just the experience of life, it’s good.”
• And if I ask if there’s still meaning in life, it’s because I’m not able to enjoy life to its full potential, um which is something I really do like to do.” |
| 147. **Unable to maintain positive attitude or outlook** | “And so uh, had I not had some strength, the strength and stamina to do that I think it would’ve worked against me, because keeping your spirits positive is very, very important when you’re dealing with this.” |
| 148. **Unable to or unsure how to modulate emotions** | • “It was just-you just felt rotten. So, and sometimes even bitchy.”
• “…with pretending that everything was fine I was like bottling it up. And then when it was time that I really wanted to release it, I couldn’t.” |
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| 149. **Unavailability of in-group support**
   Close friends or relatives are not available for support | • “I have no brothers or sisters. I have just these two children and [wife’s name] for all intents and purposes. So that’s basically the sounding board that I have to discuss, you know, matters regarding this situation or anything in life. Because I can’t sit down like with a brother or sister, saying, discuss like my personal problems or problems with regards to my parents, things like that, so…”
   • “In addition, I am 舉目無親 (jyu-mu-wu-cin) [Translator’s note: a Chinese phrase meaning not having any friend or loved one around], I felt especially lonely.”
   • “Yeah because um, ‘What is the main cause of this stress?’ I think it’s um, my family not being with me. It’s only the people friends, like you know, so it’s not as though um, um, people that I’ve known for years and years and years. It’s the people that I know for maybe a few years of my life, that’s all. So they’re not really close friends.. Especially friends that you know for only a few years, it’s not the same as friend that you grew up with.” |
| 150. **Uncertain about cancer or treatment experience**
   Uncertain about what the experience of cancer and/or treatment will be like | • “Err…I think…after you found out, when you know that you have to go for treatment, so I also know that because of my younger brother, I also know that in the future, that is there will be a lot of pain, and also a lot of things will happen. But I didn’t know how exactly it will be like, so it’s like there’s some, it’s a, err, uncertainty about the future…”
   • “I was able to get my hands quickly on the medical information I needed to satisfy my concerns, but even knowing that and reading exactly what your surgery’s going to entail, there’s still a huge amount of uncertainty…because it’s all very new.”
   • “‘Cause I was never sick before. You know, didn’t-didn’t get sick. Hm. (I: So…what was it about that was stressful?) Uh, not knowing. Not knowing where I was going from there, you know.” |
| 151. **Uncertain about cause of disease**
   Uncertain about how the disease was developed | • “…occasionally I would wonder what uh…you know I would wonder how I managed to get this particular kind of cancer when I don’t have any of the precursor things for it.”
   • “…with cancer, um…there’s not a definitive how did I get it, what causes it…” |
| 152. **Uncertain about diagnosis**
   Feeling uncertain about what his/her diagnosis would be | • “From the time they took the test to the time I found out about it, I guess it was just the stress of not knowing whether or not I had cancer or not…”
   • “I didn’t even know exactly what type of cancer I had or anything like that…” |
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| **153. Uncertain about impact on life** | • “How was it gonna affect my life…”  
• “…you have a good portion of your life hanging in the balance on the word of a test so, I’d say that’s pretty intense. Imagine if you were waiting to find out if you were pregnant. Right. That’s a big change. So yes, means one huge array of changes and uh lifestyle changes or other. And then no means similarly, changes and possible changes anyway, so…just two different paths that focus on you hearing the answer to this test. So there’s, there’s a big choose your own path right there. And uh, having to pass through that test is stressful.” |
| Uncertain about how cancer and treatment will impact life choices and lifestyle |  |
| **154. Uncertain about information needs or how to obtain it** | • “…because sometimes I didn’t know what to ask.”  
• “That is if I am one who don’t know anything, want to know but don’t know anything, also don’t know what source [sic] to look them up, and no one to help I would be so irritated that, I’d have suicidal thoughts like this.” |
| Unsure about the types of information one needs; where and/or how to get it |  |
| **155. Uncertain about length of recovery** | • “I wondered if I was ever going to get better again.”  
• “…even if I get better I don’t know, don’t know if I get better, how long it will take for me to get better.” |
| Uncertain about how long it will take to recover |  |
| **156. Uncertain about prognosis or severity** | • “Because you wouldn’t know clearly whether you can, can be treated. That is, can be healed, can be cured, cured, can get well…”  
• “Because at that time, I didn’t know about the extent of my illness condition. Right, it was just, the ENT [Note: Ear, Nose, and Throat] specialist told me, said that he found that I got cancer. It seemed that he didn’t told me exactly what stage it was. Until I had tests, tests first, before I know…at that time. Before the report [sic] came out, I didn’t know about my situation. So, therefore, it was more stressful.”  
• “Like not knowing whether or not I was going to live x number of years…”  
• “…if it metastasized, you know, would I live, right?”  
• “…how bad it was or how bad it would get.” |
| Uncertain about the chances of survival or being cured (including severity of the disease) (Note: Uncertainty includes mentioning of both positive and negative aspects) |  |
| **157. Uncertain about self care behaviours** | • “I felt like well maybe there’s something wrong, or I’m doing something wrong and uh you know I’m not following the books, and I should be doing more or something should have changed that hasn’t changed and why hasn’t it changed. So I found that hard to deal with.”  
• “…because you need to know what you’re dealing with. You need to know if the, what the do’s and the don’ts are.” |
<p>| Uncertain about which health-or self-care-behaviours one should adopt and/or whether they have been enacted correctly |  |</p>
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| 158. Uncertain about symptoms, side effects and their duration | • “…how sick, you know, would you become. You know just worrying about um, yeah, how ill you’d become that I would find stressful.”  
• “Not knowing or how long the symptoms are going to last.”  
• “It would be stressful if I didn’t know why, etcetera. If I didn’t know why, why I was being sick, why I was feeling sick. Um, if I knew why, what was, what was happening internally then I would be less stressed.” |
| Uncertain about test results | • “Well it’s while you wait it’s not knowing if it’s going to be…what kind of news you’re going to get, if you’re going to get good news or you’re going to get bad news.”  
• “…you-you-you’re always uncertain a-about what the results are going to be so naturally there’s going to be a bit of stress level.” |
| Uncertain about the future | • “…you don’t know what your future will hold so, it’s hard to make long term plans and then I have to realize you know, I didn’t know I was going to be here twenty years ago…”  
• “And like you think your whole future is gone, like you don’t know what to do.”  
• “…you don’t know what, what you’re going to do with your life…” |
| Uncertain about treatment outcome | • “And when receiving treatment, would the treatment cure the cancer or prevent any further spread or anything like that.”  
• “Because I worried about the effects of the treatment are…that is, if it’s, even if it’s 99% successful [sic], would I go into [sic] that one percent?”  
• “Well mine was uh, skin cancer in the nose but it’d had gone deep enough that it was in the septum, uh, dividing wall between your nostrils. And… ah, depending on what they found when they got in there, they ah said they might have to remove the entire nose and uh, then I’d just wear a plastic one. And that wouldn’t be uh, the ideal way to live out the rest of your life. So it was kind of I wonder what will be there when I wake up kind of a problem.” |
| Uncertain about treatment plan | • “The biggest source of stress would be, basically not knowing what you are doing. Or what the doctor would do to me.”  
• “…what the whole treatment course was about?”  
• “Just basically what the next step is. I got diagnosed and what’s going to happen next.” |
<p>| Uncertain about what's happening in my body | • “I think it would be frustrating not knowing what’s happening with your body….” |</p>
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| **164. Uncertainty due to unanswered or unanswerable questions**          | - “The crucial point was not having confirmation. Nothing was confirmed. That was because of, this situation, after all, there was no, no very definite answer.”  
- “Probably just like not really knowing exactly what was going to happen. And, not really, like, it’s kinda like if you had a doctor who could just sit next to you all the time and you could always like, ‘Oh, I just thought of a question,’ you could ask them and it would like be the right answer and then that would be great. But like a lot of the times you’re like, ‘Oh, I wonder about this or I wonder about that.’ And then you can’t really find out right away and that kind of thing and then, ‘cause like there’s some message boards so I go on the message boards on my computer and you find out like a lot of answers but then sometimes you’re like, ‘Well, that may not apply to me’ or- like so that’s I think the main cause of stress, it’s not really like having all the answers always when you want them and not really knowing exactly what’s going to happen.” |
| Experienced uncertainty from questions yet to be answered or unanswerable question |                                                                                                                                                                                                                                                                   |
| **165. Undergoing treatment**                                             | - “I was getting radiation to my face and to my neck and um towards the end, my neck was very sore and just breaking down in a sense that sometimes um it might bleed just sort of spontaneously and, and uh, and it was, it was painful and um, all you could sort of think about was can I get through tomorrow’s session, and then the next day would be can I get through tomorrow’s session and so on. So yup, that was, that was tough.”  
- “And just coping with the radiation, dealing with when I did decide to go with the radiation it was, you know, getting through the other side of that, right, the anxiousness of am I going to be able to do this? Can I pull this off, right?”  
- “That would have been my most stressful part, with the radiation therapy because you get so sick and living on my own, I had to commute back and forth to the hospital, so every day you ride the streetcar, and every day you get progressively sicker, you start covering your mouth so you can like not breath pollution and it just gets really hard. And it gets unsafe too when you really shouldn’t be on a streetcar because you could, you know you couldn’t lift someone if they fell back on you, or something like that because you’re weak and you’re tired, right.”  
- “…how I was going to get to Toronto for my treatments…where I was going to stay…” |
| Preparation for or treatment process causes suffering, including relentless ongoing demands (including practical aspects about treatment such as travel arrangements) |                                                                                                                                                                                                                                                                   |
| **166. Unexpected cancer diagnosis**                                     | - “…didn’t consider, didn’t think that I would, would, would get this kind of disease, because it was very unexpected, it was found out during routine examination.”  
- “Err…It’s mainly knowing that this disease isn’t a common disease, err, therefore then, err…that is to say, I’ve never thought that I would get this disease before, so I had a little bit of stress, when I suddenly got this disease. It’s mainly this.”  
- “Um ‘cause after I had the surgery, um I was told that um it was far more advanced than they had thought, so I think it was already at a stage 2, maybe a 3. Um but they didn’t think it was when I first went in for surgery.” |
| Surprised to receive news of cancer diagnosis or diagnosis (or extent of disease) was worse than expected |                                                                                                                                                                                                                                                                   |
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| **167. Unfairness of being discriminated against**  
Feeling of being unfairly perceived and treated based on their cancer | • “It’d be like someone you know discriminating or something like that…”  
• “…it sets up a question in their mind in terms of you know, in a business relationship, what is the long term prospects for this guy and you know what are we doing. So you have to fight that and to show that although you had a disease or you have a disease this isn’t the end, you know. And you’re fighting back and you’re as still as confident as you were yesterday, it’s just you know you are dealing with something else.”  
• “Well because there’s no reason, you can’t catch cancer. You know, so, why would they not like me? There’s no reason for that. I’d be pissed.” |
| **168. Unfairness of being ill or limited by illness**  
Feels that it is unfair that one is ill or experiences limitations due to illness and/or treatment | • “…you’ve got cancer and then you lose something because of that, you can feel like it’s unfair.”  
• “…when you want to do something and you’re just not physically capable, and you just get really frustrated thinking other people can why can’t I?”  
• “I feel like it’s um…I feel it’s slightly unfair um, that…I don’t know. It just feels sort of short-changed by having had to go through the situation I’ve gone through, sort of to create those problems. Because I don’t think that…not that there’s more people that are deserving of it, but that it’s a hard pill to swallow.” |
| **169. Unfamiliar illness experience**  
Patient encounters new and unfamiliar experiences with health problems, and/or medical procedure | • “…just the fact that it’s a new experience and uh, uh…really not u…used to dealing with, uh, having health problems.”  
• “My daugh- my oldest daughter came with me and [noise] had to go for a CAT scan to make sure that it hadn’t spread. And that was stressful ‘cause I had never had a CAT scan.” |
| **170. Unfinished business**  
Issues, responsibilities, or other items to be resolved before one will feel ready to die or face serious risk of death | • “The cause of this stress is mainly the concern of whatever I still need to do for my wife if I have to face the…the most stressful moment, like getting aesthetic because of cancer. I don’t…I do not want to leave some work left undone for myself and for the family.”  
• “Tying up all the loose ends. In the house.” |
| **171. Unpredictable course of disease**  
One cannot predict whether and/or to what extent the cancer will progress | • “Because, that is, cancer is, you can’t predict [sic] it, anytime [sic] it can, that is, recur, you don’t know. It is like a time bomb. So the biggest reason is the unpredictability. That is, bleak factors causing a person to have stress.” |
| **172. Unqualified to make medical decision**  
Lacking the medical training and knowledge to make treatment decisions | • “I’m not a medical professional and if I had to be the person to make that big decision of my own life. I wouldn’t be thrilled with that. I don’t have the same knowledge.” |
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<td><strong>173. Unsuccessful treatment</strong>&lt;br&gt;Treatment did not completely cure the cancer, resulting in feeling of futility or doubts treatment's effectiveness</td>
<td>• “The treatment was finished. It was finished in the end, it didn’t work.”</td>
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<td><strong>174. Unsure how to respond</strong>&lt;br&gt;Does not know how to answer someone’s question or respond to the situation</td>
<td>• “…if you didn’t understand the doctor and you go home and your family says, ‘Well, what did, what did the doctor say, what are you going to be doing?’ and you didn’t know enough to tell them because you didn’t understand it, it would be very stressful for you and for them.”&lt;br&gt;• “The stress is how to get myself away when you are being – when you’ve been – umm you know when you said – when somebody says something that I don’t know how to respond to, umm because I wouldn’t call-you know tell them they were you know ridiculously insensitive or anything like that.”&lt;br&gt;• “Just ‘cause you don’t really know how to handle that, then when people don’t know what to say to you.”</td>
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<td><strong>175. Unsure of how to reciprocate kindness</strong>&lt;br&gt;One has to return the kindness one has received from others during illness (including uncertain how to do so)</td>
<td>• “…because he did so much for me, I don’t know whether I can…how to…to pay back this 人情債 (ren-qing-zhai) [Translator’s note: a Cantonese term referring to debt accumulated from receiving others’ kindness and assistance] in the future.”</td>
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<td><strong>176. Unwanted help, support, or attention</strong>&lt;br&gt;Received unnecessary or undesired help, support, or attention due to illness</td>
<td>• “I do have these close friends but they weren’t…I didn’t really want people around. Sometimes when you’re that sick, you don’t want people around, even though you feel lonely, but you don’t. It would have been more of a chore to have somebody there because then I would have worried about how, you know…I would have worried about them.”&lt;br&gt;• “I am a relatively private person, I don’t really like to share my, my you know, if somebody asks me you know, ‘How are you doing?’ I, it’s not something I ask other people, so I always consider that a personal, personal thing, so it was mostly maybe, infringing into my, into my personal life.”&lt;br&gt;• “They kept reminding me ah that you can only do this and don’t push yourself too much, like, doing all the parent thing. It was pretty, I’d say like ah I was two years old or three years old all over again.”&lt;br&gt;• “…people are paying lip service to you, you know that they’re just stroking you ‘cause, ‘Oh Jesus you got cancer, you’re gonna die next month,’ so they’re being ultra nice and you really don’t want that, you really don’t so, again, they put you in another group of human beings.”</td>
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<td><strong>177. Victim blaming</strong>&lt;br&gt;Blame the victim for his/her own illness</td>
<td>• “I think people say some stupid things. Umm and if I was umm if I didn’t know how to respond to it- umm that would kind of be the most stressful. Well comm-ah- ah – blaming comments. So that you know, ‘If you had-well if you’d only done this,’ and I’m thinking like how stupid can you be? You know a-and if I’m dumbfounded it-it I’d be stressed by inability to respond. Umm but, and I do remember umm people having some umm blaming comments or, inadvertently blaming.”</td>
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<td><strong>178. Waiting for medical information</strong>&lt;br&gt;Stresses associated with waiting for disease and/or treatment information</td>
<td>• “The most stressful part was waiting. Because I had the surgery and the biopsy of the tumour took, was taking a long time, like it took two months, it took three months, and it took four months…”&lt;br&gt;• “I understand that, that things take time. I understand that if they do a biopsy it takes, you know, 9 to 10 days for the result to come back. But just waiting for that answer in those time periods. It’s difficult.”&lt;br&gt;• “Initially, it was the fact that it took so long to be diagnosed. They took a year and that really pissed me off.”</td>
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<td><strong>179. Waiting for treatment or test</strong>&lt;br&gt;Stresses associated with having to wait to receive treatment / test</td>
<td>• “Just wanting to know what’s next, results were gonna be, which tests find out the next results ‘cause you’re waiting in line to get the next tests done and you can’t get the next tests done until you get that appointment that can be weeks or months away, which for my time-frame it was.”&lt;br&gt;• “…because it, it took a, a long time to get the schedule-scheduling for the uh, radiation treatment and all that so it, it all became stressful.”</td>
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<td><strong>180. Weighing the choices</strong>&lt;br&gt;The process of thinking through the alternatives for treatment</td>
<td>• “…there’s limited information available and you get to a point where you have to start differentiating between what is really helpful for you and what is not. Because then people start coming to you with all these other ideas, like home-therapy, nature therapy, new drugs, test drugs, stuff from the States, from Mexico and Europe. You hear all this kind of stuff and you have to try and filter through what sounds plausible or not. You gotta do a balancing act. You can’t just keep running off to, I mean it’s as if they can cure you. What is fact and fiction.”&lt;br&gt;• “…the radiation was less invasive, so it’s just sitting, weighing everything out, but it’s like anything in life, like you come to choices, not just with this, but with anything. And you can go left and you can go right and you have to sit. So the stress is sitting there you know thinking you know OK, what are the pros of doing this, what are the cons of doing this, you know right.”&lt;br&gt;• “…choosing between radiation, or surgery, ah, [pause] with, ah, differing medical opinions as to which was the preferable way to go. And ah…in my case trying to decide for instance if I, if I adopt that sort of recommendation is it to have ah eight years roughly of looking relatively normal but then all hell breaking lose or ah saying no we’re gonna do the surgery now and hope it goes alright and if it does then I’m not gonna look great but I won’t look too bad for longer than that.”</td>
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| **181. Why me?** Cannot make sense of why one has developed cancer (e.g. questioning why one has cancer). Responses can, but need not include emotional tone (e.g. frustration, fear). When this stressor appraisal is expressed in a way that articulates a sense of unfairness, responses are categorized as “why me” | • “Just why me, more or less thing, uh why’d this happen to me…”  
• “I felt, ‘Oh, why was I unlucky, encountered this kind of things?’”                                                                                                                                 |
| **182. Wondering about the cause of physical limitation** Questioning why one cannot do certain activities | • “I want to do something, can’t do it, the source of stress, then actually perhaps I would ask myself, ‘Why can’t I do it? Is it because I have cancer? Is it because of natural causes? Is it because of getting old so I can’t do it?’” |
| **183. Worried about invalidating test results or compromising treatment effectiveness** Patient fears his/her behaviours (or lack of behaviour) may have compromised the test or compromised treatment effectiveness | • “…the radiation required me to prepare in the way of going on a special diet and what have you. And I think I was just worried, you know, what if I ate something that won’t work well with the radiation, or you know, ‘cause I was supposed to avoid sodium and salt and all that, so I thought, I wonder if that has salt in it naturally and just not being very, my big thing was I wanted to be meticulous and accurate with whatever the doctors told me so I think what stressed me out was what if I broke a rule without realizing it. Like I even remember in the hospital, I went in and I couldn’t have milk or dairy before my radiation and then they said you know, about an hour or two after you can start having that, and so I hadn’t eaten that morning so I was really, really hungry and really, really tired. Because naturally I would be tired and I, I hadn’t had a coffee in like 14 days. So after that they said, ok you can have coffee and I, but I thought oh did I have my coffee too soon you know because it had milk in it. Did I screw up the radiation, the effect, the effectiveness of it, you know.”  
• “‘Cause you’d be worried of doing the wrong thing. You’d be worried of saying, ‘Am I supposed to take two of those pills today or one today?’ Or did I, you know, you’d be second guessing it, and you’d think, well, is this gonna effect my health? Like…that sorta thing. That’s, that would, that probably would be a, be a serious concern. ‘Ok, well I thought you said to do this,’ and then all of a sudden, you’ve, you know, ruined all the work that’s been dug out of the mound, that sort of thing, ya.” |
| **184. Worrying may worsen family member’s health** Worrying about patient’s illness may cause negative effects on family member’s health | • “I guess I worry about what it might be doing to him, and other people in my family. How they might be worrying and how it could affect their health by worrying about me.” |
Appendix H

Stressor appraisal coding codebook
Stressor appraisal coding (Stage 1) code book

Instructions

You have been asked to assign each of the following stressor appraisals (in column #1) to predetermined categories. A stressor appraisal is a reason that a particular cancer stressor is perceived as “stressful.” In the following table, each stressor appraisal has a label (in bold) and a conceptual definition. Exemplars (i.e., interview excerpts that best reflect the particular stressor appraisal) of each stressor appraisal can be found in one of the attached documents. You can use all this information to help make decisions while coding.

In Stage 1 coding, please assign each stressor appraisal to one of two mutually exclusive categories, “Relevant to values” (in column #2) or “Irrelevant to values” (in column #3). Category assignment should be based on whether a stressor appraisal reflects any of the following values:

- **Camaraderie with co-workers:** Concern for the well-being of someone with whom one has a collegial relationship (i.e., colleagues, co-workers; but not friends);

- **Commitment to family:** Dedication to maintaining the well-being and meeting the needs of one’s family (including prioritizing these above one’s own if needs be). “Family” refers to one’s spouse, parents, siblings, children, and extended relatives; or

- **Competitiveness:** Desire or ability to achieve more than others in a competitive context.

Procedures:

Using on the conceptual definition and exemplars provided in the attached document, please assign each stressor appraisal to the “Relevant to values” category when it reflects any of the above values. Please enter the number “1” in the corresponding cell. When a stressor appraisal does not reflect any of the values, please assign it to the “Irrelevant to values” category by entering the number “1” in the appropriate cell.

Please enter your coding on both the hardcopy and the electronic versions of the following table.

*Special circumstances and how to handle them:

If a stressor appraisal refers to a non-specific target (i.e., when the person(s) to which a stressor appraisal refers), such as “others,” the item can be applied to any group of people (i.e., family, friends, or others). Please do not rely only on the target mentioned in the stressor appraisal and its definition to establish the category to which the stressor appraisal should be assigned. For example, if the (hypothetical) appraisal is “family moving on with their lives,” the stressor appraisal reflects the cancer patient’s family wanting to move on with their lives. The patient
may feel stressed about this, but it does not threaten the patient’s commitment to his family. Therefore, this stressor appraisal should be categorized as “Irrelevant to values.” If the (hypothetical) stressor appraisal is “holding back my family from moving on with their lives,” this would reflect that the cancer patient felt responsible for his family’s inability to carry on with their lives, which is something that would compromise their well-being. Thus, the second (hypothetical) stressor appraisal should be categorized as “Relevant to values.”

We have tried to make as explicit as possible subtle differences among the stressor appraisals, but they are abstract concepts that require subjective judgment (unlike coding for more concrete variables such as sex). If you find it difficult to code any of the stressor appraisals, please do your best to assign it to the one category to which you believe it provides the closest fit. To help us document the causes of such difficulties, please use the attached form to record all instances in which you found it difficult to code a stressor appraisal. Please state all of the reason(s) for the coding difficulties you experienced and explain what led you to assign the particular category you finally selected for each of the challenging stressor appraisals.
### Stressor appraisal coding form for STAGE 1 CODING

**Sample form**

<table>
<thead>
<tr>
<th>Name and conceptual definition of stressor appraisal</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Relevant to values</td>
</tr>
<tr>
<td>1. <strong>Abrupt change to lifestyle</strong></td>
<td></td>
</tr>
<tr>
<td>Sudden change to one's lifestyle</td>
<td></td>
</tr>
<tr>
<td>2. <strong>Afraid of death</strong></td>
<td></td>
</tr>
<tr>
<td>Fear associated with the meaning and experience of death, e.g. slow and lingering death, and what happens after death</td>
<td></td>
</tr>
<tr>
<td>3. <strong>Allowing others to know about vulnerability (or anxiety about doing this)</strong></td>
<td></td>
</tr>
<tr>
<td>Letting others know that you are vulnerable or in need (or anxious about doing it)</td>
<td></td>
</tr>
<tr>
<td>4. <strong>Anticipating loss of valued relationships after death</strong></td>
<td></td>
</tr>
<tr>
<td>Anticipation of loss of relationships after death</td>
<td></td>
</tr>
<tr>
<td>5. <strong>Anticipating or receiving unfavourable test results or news</strong></td>
<td></td>
</tr>
<tr>
<td>Anticipates that one's medical test will yield an unfavourable result, or receiving such results or news</td>
<td></td>
</tr>
</tbody>
</table>

### Difficult-to-code stressor appraisal documentation form

**Sample form**

<table>
<thead>
<tr>
<th>Stressor appraisal ID # &amp; label (cut-&amp;-paste from table)</th>
<th>Why it was difficult to code in the first place?</th>
<th>Why did you coded it in the current category?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix I

Interview excerpt coding codebook
Interview excerpt coding (Stage 2) code book

Instructions

In Stage 2, you are asked to assign each of the following interview excerpts into one of four categories depending on their relevance to these values:

- **Camaraderie with co-workers:** Concern for the well-being of someone with whom one has a collegial relationship (i.e., colleagues, co-workers; but not friends);

- **Commitment to family:** Dedication to maintaining the well-being and meeting the needs of one’s family (including prioritizing these above one’s own if needs be). “Family” refers to one’s spouse, parents, siblings, children, and extended relatives; or

- **Competitiveness:** Desire or ability to achieve more than others in a competitive context; or,

- **Irrelevant to values:** the excerpt does not reflect any of the above values.

To be “relevant” to a value means that a stressor appraisal reflects a situation that is in contrary to one of these values. Specifically, if a stressor appraisal prevents one from acting (or causes concern that one may not be able to act) in accordance with one of these values, then it can be deemed as “Relevant to values.” For example, if a stressor appraisal impedes one from caring for one’s family, then the stressor appraisal should be categorized under “Relevant to values.”

**Procedures:**

Using the information available to you from the excerpts, categorize each of them into the above categories. If an excerpt is relevant to a particular value, please indicate it by entering the number, “1,” in the corresponding cell. If an excerpt is not relevant to any of the values above, please indicate it by entering the number, “1,” in the appropriate cell under “Irrelevant to values.”

You must enter your coding on the hardcopy and electronic versions of the following table.

**Special circumstances and how to handle them:**

There may be instances where the overall meaning of an excerpt fit with one of the values but the excerpt refers to a different target; for example, an excerpt may reflect one’s dedication to maintaining the well-being and meeting the needs of one’s friends. Though its meaning is very similar to “Commitment to family,” since the excerpt refers to one’s friends, it should be coded as “Irrelevant to values.”

There may be other instances where the target referred to in the excerpt is ambiguous, such as “others,” or is not explicitly mentioned. In these cases, the coding should be done based on the excerpt’s relevance to the values. If the meaning of the excerpt fits with one of the values, then it should be assigned that corresponding value category. Since these categories are not mutually exclusive, an excerpt may be categorized under more than one of the following categories: (a) Camaraderie with co-workers; (b) Commitment to family; and (c) Competitiveness. This may be the case when the target in the excerpt is ambiguous. There should not be a situation where an excerpt is coded under one of the value categories and “Irrelevant to values.”
If you encounter difficulties with coding any of the interview excerpts, do your best to place it in one of the categories. To help document any causes of these difficulties, please record (on the attached form) all the instances that you found it challenging to code these excerpts. State the reason(s) for these coding difficulties and explain how you decided on which category to code these challenging excerpts.
## Interview excerpt coding form for STAGE 2 CODING

### Sample form

<table>
<thead>
<tr>
<th>Excerpt #</th>
<th>Excerpt ID</th>
<th>Excerpt</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Commitment to family</td>
</tr>
<tr>
<td>1</td>
<td>003S7E1</td>
<td>they’d be afraid that I’d be broken-hearted, not knowing how to comfort me.</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>017S3E1</td>
<td>Because, because I can’t, can’t stop working, because working is the source of life (/income).</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>017S4E2</td>
<td>when you are sick you would feel that you are, a bit different from others, I guess this difference is my stress, right. I don’t wish, that is to say others see me, they would need to take care of me, because I got this disease or got cancer (sic), this, I think it doesn’t, doesn’t need this.</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>027S7E5</td>
<td>When there’s nobody around, you would that is, would think, “Why should I still be here? Better being dead!” That is since no one is there to pay attention to you, at that time I would think like that.</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>027S1E5</td>
<td>How will I tell other people, or how do I explain it to my office (sic).</td>
<td></td>
</tr>
</tbody>
</table>

Note: underlined [sic] sections are reproduced verbatim from Chinese transcripts.

## Difficult-to-code stressor appraisal documentation form

### Sample form

<table>
<thead>
<tr>
<th>Excerpt # &amp; ID (cut-&amp;-paste from table)</th>
<th>Why it was difficult to code in the first place?</th>
<th>Why did you coded it in the current category?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>