**Title**

Understanding Domains of Health-related Quality of Life Concerns of Singapore Chinese Patients with Advanced Cancer: A Qualitative Analysis

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**ABSTRACT**

**Purpose:** Quality of life concerns in patients with advanced diseases might be different from other patients and is shaped by socio-cultural context. The objective of this qualitative study was to identify domains and themes of health-related quality of life (HRQoL) that Chinese patients with advanced cancer in Singapore considered relevant and important.

**Methods:** English- and Chinese-speaking patients with advanced solid cancer were recruited from a tertiary cancer centre and a community-based hospice for in-depth interview or focused group discussion. Thematic analysis was used to identify sub-themes, themes and domains from the transcripts.

**Results**: Forty-six ethnic Chinese (aged 26-86, 48% male) participated in the study. Six domains of HRQoL concerns were identified: pain and suffering, physical health, social health, mental health, financial well-being and spiritual health. Pain and suffering are not limited to the physical domain, reflecting the multi-dimensional nature of this concept. Pain and suffering must also be understood within the cultural context. Healthcare relations (i.e. Social Health), existential well-being and religious well-being (i.e. Spiritual Health), and suffering (i.e. Pain and Suffering) are not fully captured in the existing HRQoL instruments. In addition, financial issues and the practice of secrecy in interpersonal relationships emerged as unique features possibly arising from our socio-cultural context and healthcare financing landscape.

**Conclusion***:* Socioculturally specific issues not measured by the existing HRQoL instruments for use in patients with advanced cancers or terminal diseases were found in our study. These are non-physical pain and suffering, meaning of illness, meaning of death, financial issues and practice of secrecy in interpersonal relationships.

**Keywords** Advanced cancer, Chinese, quality of life, qualitative research, psycho-oncology

**INTRODUCTION**

Health-related quality of life (HRQoL) is the primary outcome of palliative care [1]. Over the years, there has been an increasing recognition to adopt a broader mandate in cancer care: to attend to patient’s HRQoL instead of focusing exclusively on fighting the disease. In response, the last few decades saw rapid development of HRQoL instruments in an effort to improve assessment of patient health and well-being. Traditional HRQoL instruments tend to emphasize symptom control and physical functioning. Current HRQoL instruments such as Assessment of Quality of Life at the End of Life (AQEL), Functional Assessment of Chronic Illness Therapy – Palliative Care (FACIT-Pal), Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being, Expanded version (FACIT-Sp-Ex), McGill QoL Questionnaire, McMaster QoL Scale, Missoula-VITAS quality of life index and Quality of Life at the End of Life (QUAL-E) measure HRQoL holistically. [2-7].

HRQoL is a multi-dimensional construct, which reflects the extent to which one’s physical, mental, social, and spiritual well-being are affected by a medical condition and its treatment [8]. A task force on good research practices considered inputs from the target population during instrument development as essential to establish the content validity [9, 10]. Despite the wealth of studies on HRQoL instruments, none of the instruments aforementioned was developed based on the Asian population with patient inputs, though validation studies have been conducted in patients with cancer or who were terminally ill in Hong Kong, Japan and Korea [11-13]. There is a need for a qualitative study that will inform a culturally relevant and important HRQoL domain/theme framework to assess the holistic well-being of patients with advanced cancer in Singapore.

Qualitative methods such as individual in-depth interview and focus group have emerged as the standard methodology for developing items and domain framework and supporting content validity for new HRQoL instruments [14]. We sought to identify HRQoL domains by means of individual in-depth interview and focus group, through which we explored participants’ subjective experience of what constitutes a good HRQoL for them. This article reports the results of this qualitative study and presents the HRQoL domains that were found important to patients with advanced cancer.

**MATERIALS AND METHODS**

**Participants**

Patients were recruited from the outpatient clinic at the National Cancer Centre Singapore (NCCS) and HCA Hospice Care (HCA, a non-profit organization in Singapore providing home-hospice care to patients with life-limiting illnesses). Inclusion criteria were: 1) a diagnosis of advanced solid cancer, 2) age 21 years or older, 3) ethnic Chinese, 4) aware of diagnosis and prognosis, 5) no evidence of psychosis, major depression or delirium, 6) able to communicate in Mandarin (official spoken form of Chinese) and/or English, and 7) willing to be voice recorded. We only recruited Chinese patients because they form the majority of our target population and because of the language limitations of the interviewers. Written informed consent was obtained from each participant before interview. The Institutional Review Board of the National University of Singapore approved the study.

**Data Collection**

Doctors or nurses identified eligible participants, and a research coordinator obtained written consent from the participants. A focus group was arranged if the participants’ time schedule and mobility allowed. Alternatively, an individual interview was arranged. Altogether, 28 participants were individually interviewed and 18 participants attended six focus group sessions, comprising two to four participants each. For each focus group, we aimed to have minimally four attendees. However, absenteeism at the 11th hour was common due to the participants’ frail condition. A team of seven interviewers/facilitators conducted the interviews and focus groups, including four practicing social workers, one nurse, and two authors (GLL and HLW). GLL and HLW are experienced qualitative researchers and have professional qualifications in social work and pharmacy, respectively. To minimize heterogeneity in interviewing, we conducted two training sessions – one before the study began and one during the study. The trainer (GLL) reviewed the interview recordings for the first two interviews conducted by each interviewer and provided feedback.

The interview/focus group began with a broad, open-ended question (How has cancer/cancer treatment affected you?) to minimize the influence of interviewer/facilitator probes [14], and progressed to questions regarding specific HRQoL areas (e.g. emotional aspects). References were made to the domains identified in the seven instruments aforementioned for specific HRQoL questions (Appendix A). All the interviews/focus groups were conducted in English or Mandarin according to the participants’ language preference, except for one focus group, which was conducted in Mandarin initially but drifted into a mixture of Mandarin and Cantonese as the session continued. Cantonese is a common Chinese dialect used among the older generations in Singapore and the elderly participant used Cantonese intermittently to express her views. The interviewer is fluent in English, Mandarin and Cantonese. All the interviews/focus groups were completed in a single session, lasted on average 90 minutes.

Quotations in the manuscript may appear grammatically incorrect due to colloquial use of English (e.g. <http://en.wikipedia.org/wiki/Singlish>). To keep the cultural essence, in this manuscript we made minimal grammatical corrections when necessary. The Chinese interview transcripts were translated into English by one author, verified independently by another author, and discrepancies were resolved through a consensus meeting between the two authors. We did not conduct a formal forward-backward translation. The two authors (GLL and HLW) compared the findings of our current study to the seven HRQoL instruments aforementioned independently, and the third author (YBC) resolved the discrepancies.

**Data Analysis**

Audio recordings of the interviews and focus groups were de-identified and transcribed before they were coded by the coders. The coded transcripts were subsequently imported and further analyzed by the authors using NVivo Version 10.

***Defining HRQoL.*** We defined HRQoL broadly as descriptions made by patients on their experiences of the illness and how specific aspects of their life have been affected. We made a clear distinction between factors contributing to poor HRQoL and the experienced HRQoL and excluded the former when developing the coding framework. For example, in this excerpt:

‘I feel very lethargic. [When] my friends ask me to go out, I say “Can you come to my house instead? I don’t feel like going out. It’s so tiring.”’ (E17)

The first sentence was considered description of the symptom *Fatigue*, which was a factor affecting quality of life rather than a HRQoL theme. The second sentence was defined as a HRQoL sub-theme *Adjustment in social activities*.

***Codebook development.*** For trustworthiness and authenticity check purpose [15, 16], three authors (GLL, HLW, MYLO) coded randomly selected transcripts independently. Each transcript was coded by at least two authors. The codes were compared and agreement was reached via consensus meeting. The initial codebook developed comprised five ﬁelds (code title, deﬁnition, examples, inclusion/exclusion rules, and relationship to other codes). An inductive process was also utilized to expand and refine the codebook so that new, emerging themes were reflected. Coders were trained to code the transcripts using the codebook. Coders were paired and coded sample transcripts independently. Two authors then independently reviewed the coded transcripts to assess coding quality. All six coders were evaluated in this process and further training was provided where needed. The six coders then coded the transcripts individually.

***Initial coding, focused coding and axial coding.*** Thematic analytical method was used to identify and analyse themes within the data, through the process of initial coding, focused coding and axial coding [17, 18]. Initial coding was the first stage of data analysis; a line-by-line coding using a data-driven approach with the aim of being open to investigating theoretical possibilities and doing codes that followed closely to the data. This was followed by focused coding, which involved categorizing the most significant and frequent initial codes into themes and sub-themes. Finally, axial coding was used to synthesize and re-assemble the themes into domains to give coherence to emerging analysis at the conceptual level [18]. At this stage, the domains described in the seven HRQoL instruments aforementioned informed the theoretical framework for the study. The final output of thematic analysis was a hierarchical ordering of concepts with a (sub-)subtheme being the most specific concept and finally a domain being the broadest classification. In vivo codes in single quotation marks were used as evidence when appropriate. Prefix E (for English) or C (for Chinese) in participant numbers in quotations indicates the language of interviews.

**RESULTS**

From April to November 2012, we recruited 46 patients with advanced cancer: 31 from NCCS and 15 from HCA. The mean age was 59 years. The participants were predominantly married (65.2%), female (52.2%), Buddhist (45.7%), and had obtained General Certificate of Education (GCE) “N’ or “O” Levels (37.0%). Breast (41.3%), colorectal (15.2%) and lung (13.0%) cancers were the most common primary cancer diagnoses; the remaining 30% included various cancer diagnoses (Table 1). Interviews occurred in English (21 participants) and in Chinese (25 participants).

Analyzing the data, the coders identified six domains of HRQoL: *Pain and Suffering*, *Social Health*, *Mental Health*, *Spiritual Health*, *Financial Well-Being* and *Physical Health*. The domain *Pain and Suffering* is presented in more detail as it featured prominently. The other five domains are presented in less detail for brevity, only highlighting certain aspects that we thought were either different from similar categories in published literature or unique to our study. Table 2 summarizes the findings in terms of the domains and their content. Table 3 presents exemplars for all the themes.

**Pain and Suffering**

*Pain and suffering* is an interesting and complex domain as the findings cut across various domains of HRQoL, reflecting the multi-dimensional nature of this concept. Simultaneously, it also needs to be understood within the cultural context. Four themes were found in this domain: *Physical pain and suffering*, *Mental pain and suffering*, *Existential pain and suffering* and *Welding pain and suffering syndrome*1*.* Physical pain and suffering were reported when the participants were in physical pain, such as bone pain or insertion of needle during chemotherapy:

‘Sometimes I may really suffer, and if possible, I try not to let people know that I’m really suffering…suffering in the physical pain. My physical pain [is my] main concern.’ (E36)

Mental pain and suffering were reported, for example, when life was all about counting down to chemotherapy days or when the illness impact went beyond participants and included their loved ones:

‘I’m sure you don’t want to see your own family people, your loved one suffer. This kind of suffering is called mental suffering.’ (E45)

Pain and suffering took on existential meanings described by the participants as meaningless or a solitary experience. The participants faced it essentially alone, probably at the most vulnerable time of their lives:

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1. The authors have newly coined a specific patient's illness experience as 'welding pain and suffering syndrome' when patients' self-report of their illness experience, as expressed by the Chinese terminology *'tong-ku'*, denotes an expression of their inner heartfelt pain and suffering. It is the fusion (welding) of existential, emotional and physical expression of pain and suffering that forms a distinct clinical landscape (syndrome). From a medical perspective, syndrome suggests a combination of symptoms resulting from a single cause or so commonly occurring together as to constitute a distinct clinical picture.

‘Your family, your friends, might be beside you, still, the suffering is yours…it’s good to have someone with you, but it is still your own [suffering].” (E42)

Finally, the theme *Welding pain and suffering syndrome* carried the Chinese cultural meaning. “*Tong-ku”* (Chinese phonetic transcription) or 痛苦 (Chinese characters) was the phrase commonly used by the participants when they described their pain and suffering in Mandarin. Literally, the first Chinese character denotes “pain” and the second denotes “bitterness”. However, the meaning of the first is not limited to physical pain and the second character is often used to denote hardship. More importantly, *tong-ku* depicts the co-existence of physical, mental and existential elements of pain and suffering. Excerpts C29 and C32 illustrated the importance of viewing physical, mental and existential elements of pain and suffering as one entity of meaning making within the Chinese cultural context. In the excerpt C32, the emotional expression of mental and existential pain and suffering (not able to move) even appeared before physical discomfort (bed sores).

‘Sometimes when [I am] in pain, when [I] feel most *tong-ku*, [I] tend to think too much and entertain thoughts of “Why not just die now?” This is because nobody can share the burden of pain with me; I can only rely on myself.’ (C29)

‘I am also *tong-ku*. I’m lying there and I could not move, and then I have bed sore and so on...’ (C32)

**Social Heath**

*Social Health* refers to the interpersonal relationships of the participants, from which three sub-domains were formed: *Family Relations,* *Social Relations*, and *Healthcare Relations*. Within each of these three subdomains were two widely-reported themes, *Support* and *Quality of relationship*, although these themes had different subthemes. For example, *spousal support* was present in the *Family Relations* subdomain only; *employment support* was present in the *Social Relations* subdomain only; *informational support* was present in the *Healthcare Relations* subdomain only. Similarly, for the theme *Quality of relationship,* *changes in the family relationship* was present in the *Family Relations* subdomain only; *neutral* was present in the *Healthcare Relations* subdomain only. (Tables 2 and 3).

***Quality of relationship.*** “*Presence of secrecy*” in interpersonal relationships was a common form of negative relationship reported in the *Family Relations* and *Social Relations* sub-domains. The illness was kept as a secret from friends or only disclosed to selected friends, mainly to protect self from stigmatization. Secrets also existed within the family when emotion or pain was kept within the participants, though the intention was to protect the family from emotional distress:

‘[I] look quite healthy, [I] look quite happy, because sometimes [I] don’t want to show any pain or discomfort in front of children. [I] try to hide it, don’t let them know.’ (E20)

**Spiritual Health**

A broad definition of spirituality is adopted in this study and it includes religious and existential aspects such as an appreciation of life, relationship with God/Higher Power, self, hope, meaning and purpose in life [19]. *Spiritual Health* refers to feelings of spiritual distress, which can be expressed as negative feelings and positive spiritual experiences. Two sub-domains emerged: *Existential Well-being* and *Religious Well-being.* The themes discussed were *Death and dying concerns,* *Meaning of death, Meaning of illness, Meaning of life,* and *Relationship with God/Higher Power* (Tables 2 and 3).

***Meaning of Death.*** Positive and negative meanings of death were discussed by the participants, which included death as a natural ‘path’ to go eventually, as a transition and as an ‘escape’ or as an ‘end to everything’.

***Meaning of Illness***. Though less often reported than the other themes described in the *Spiritual Health* domain, positive and negative meanings of illness were reported by some participants. For example, two participants stated that it was their ‘fate’ to be ill. One other participant believed that having cancer taught her to ‘lead her life’.

***Relationship with God/Higher Power.***Positive changes in the *Relationship with God/Higher Power* were commonly reported among the participants. The three subthemes identified included *religious comfort*, *religious support* and *religious healing*. The discussion was mainly on *religious comfort*, where the participants reported a closer relationship with God/Higher Power, in which they found extreme happiness. In *religious support*, the participants reported that their religious beliefs had given them strength and sustained them in living with cancer. In *religious healing*, the participants reported a miraculous relationship with their God/Higher Power:

“I believe in Him because I have seen a miracle once... I’m convinced.” (C43)

**Financial Well-Being**

*Financial Well-Being* refers to the feelings of financial stress and financial comfort. Three themes that emerged included *Financial concern*, *Financial assistance*, and *Financial comfort*. Financial concern was one of the biggest worries found among the participants as ‘everything is about money’. The two main sources of financial assistance reported were informal resources such as siblings and formal resources such as the government. However, not all the participants reported financial stress; some were financially comfortable as they had a constant source of income, had no financial responsibility or were financially sound (Tables 2 and 3).

**Mental Health**

*Mental Health* refers to the applied cognition and feelings of emotional distress and positive emotional experiences. The two subdomains were *Cognitive Health* and *Emotional Health*, which were informed by the following themes and (subthemes): *Cognition* (attention/concentration, executive functioning, learning), *Self-concept* (positive or negative, altered self-image)*,* and *Emotion associated with illness* (e.g. anger, helplessness, worry)(Tables 2 and 3).

**Physical Health**

*Physical Health* refers to self-perception of the physical functioning or the physical ability/disability to do things, which is a similar to the seven instruments reviewed (Tables 2 and 3).

**DISCUSSION**

This study identifies numerous physical, social, mental, financial, spiritual issues that Chinese patients with advanced cancer in Singapore experienced specifically as a result of the illness and treatment.

Findings of this study largely agree with the framework of the seven HRQoL instruments aforementioned. The physical, social, mental and spiritual domains could be found collectively in the seven HRQoL instruments, although they may be categorized somewhat differently. The present findings also identified domains/items that are unique or different from the current literature (Table 2).

First, our observation that pain and suffering are beyond the physical domain and include mental and spiritual domains concurred with Saunders’s concept of “total pain” [20]. The “Welding” concept of pain and suffering can be seen as a new subset of the total pain concept. In the English language, the themes could be clearly differentiated into physical, mental and existential pain and suffering, thus rightfully could be discussed in the domains *Physical Health*, *Mental Health* and *Spiritual Health* respectively. However, the Chinese language tends to be a “suggestive” language and to have multiple meanings for a term [21]. In the Chinese culture and language, the physical and mental aspects of pain and suffering are inter-related [22]. Previous studies on validation of the SF36 health survey conducted in the West and Asia had illustrated this cultural difference. In Western societies, the measurement model of SF-36 reflects that the general population conceptualized HRQoL as two distinct components: physical health and mental health. Contradictorily, Asian studies (Singapore, Japan and Taiwan) showed no such clear differentiation; physical and mental health matters are intertwined. For example, bodily pain correlated with the physical and mental components [23-25]. This concurred with the holistic concept of health in Asian societies. Moreover, the traditional cultural values put a strong emphasis on concepts such as Buddhist and Confucian virtues of “enduring” suffering, when suffering is said to be inherent in the life processes in Buddhist traditions [22, 26]. We postulate that there are similar HRQoL concerns in other Asian societies where Buddhism is a popular religious belief.

Second, our study suggests that secrecy in interpersonal relationships or even within family is common. Secrecy is a strategy at the other end of disclosure continuum when managing information which is socially considered a stigma within a culture or which has a direct impact on one’s well-being [27]. Of the seven instruments reviewed, the FACIT-Pal (version 4) is the only scale that has an item related to secrecy under ‘Additional Concerns’: ‘I am able to openly discuss my concerns with the people closest to me’. It is interesting to note that secrecy in interpersonal relationships was also common among the Latino culture [28], but in ways different from what was practiced in our Chinese patients. Latino caregivers were found to prefer not knowing the details of the dying process from the physicians, and to keep the prognosis a secret unknown to the patient [28]. In our study, patients were the ones who practiced secrecy. They reported that secrets were kept from friends for self-protection and from their family members to protect the family members from emotional distress. In the Asian context, the concepts of dignity (尊严or *zun-yan*) and face (面子or *mian-zi*) are associated with social support. “*Zun”* means “respect” and “*yan”* means “rigorous”, thus dignity in the Chinese society implies a deep respect and honor in an interpersonal relationship, which is governed by behaviors that are related to enhancing, saving and losing face [29]. It is interesting that there is a greater emphasis on collective identity in both Asian and Latino cultures [30].

Third, the *Healthcare Relation* subdomain seems not fully captured by the seven HRQoL instruments, with only the AQEL using two items to capture support and QUAL-E using one item to capture support and two items to capture quality of relationship. This is similarly found for the *Religious Well-Being* subdomain, which was only captured in FACIT-Sp-Ex (Version 4).

Fourth, although the theme *Meaning of life* was commonly captured in the seven HRQoL instruments, the themes *Meaning of death* and *Meaning of illness* were not found in any of the seven instruments. The themes found on *Meaning of death* from our study seem to concur with the concepts “neutral acceptance”, “approach acceptance ” and “escape acceptance” measured in the Death Attitude Profile-Revised (DAP-R), a scale widely used to measure death attitudes [31].

Fifth, financial concerns are one of the biggest concerns highlighted by the participants in our study. Yet it is not a common item in the seven HRQoL instruments apart from QUAL-E. We believe it is related to the healthcare financing mechanisms in Singapore where patients incur a substantially larger proportion of out-of-pocket payments (60.4%), compared to, for example, Canada (14.4%) and France (7.5%) (in 2011) [32].

**Limitations**

We recognized that there are limitations to this study. We did not use a forward-backward translation approach when translating the Chinese transcripts. We also did not quantitatively evaluate the inter-coder reliability. However, we used alternative measures to control the quality of the translation and coding processes. Lastly, the generalizability of the findings is limited to the Singapore Chinese patients with advanced cancer; that is, patients with metastatic cancer and not receiving treatment for curative intent. However, due to similarity in culture and language, we speculate that the findings may be generalizable to patients with advanced cancer in ethnic Chinese populations elsewhere. Further research will be needed to verify that.

The findings from this study have important implications. They suggest a need to develop a HRQoL instrument specifically for the Chinese population in Singapore as existing instruments collectively, but not individually, measure most of the HRQoL concerns identified in our participants. We are aware that several studies have reported the cross cultural adaptation of HRQoL instruments among Asian patients with advanced cancer care [11-13]. However, psychometric properties were the frequent focus, which included reliability and the ability to differentiate between groups that are expected to have differing HRQoL, with less attention paid to content validity and cultural relevance. The latter often requires qualitative studies. There are also unique HRQoL concerns in this population that are clearly less important in the Caucasian population for which most instruments are developed. The present study provides the domain/theme framework for this development. Based on these findings, we intend to develop a local instrument as the next step of this series of research. The differences between some themes and subthemes are subtle, which are somewhat overlapping. However, the list generated provides a useful domain/theme framework for development of a local HRQoL instrument for the Chinese patients with advanced cancer or life-limiting illness. The findings will help HRQoL assessors to make informed choices and usages of existing instruments according to the content validity of the instruments and the specific aspects of HRQoL that they may focus on.

In conclusion, this study reveals domains and themes of HRQoL important and relevant to Singapore Chinese patients with advanced cancer. While many of the HRQoL aspects that are measured by existing instruments for use in patients with advanced cancers were found in our study, non-physical pain and suffering, social relation (i.e. secrecy), healthcare relation and issues related to meaning of illness and death were not fully captured.

Appendix A

Focus Group/Interview Guide on Cancer related Health Related Quality of Life

1. Can you please share with me how cancer or cancer treatment has affected your life generally? (probes: physical, social, psycho-emotional, spiritual, financial and cognitive aspects)
2. What is bothering you most currently?
3. Can you share with me more about your experience with the doctor or other health professionals?
4. Now, I would like to find out what do you like best about your life? (probes: physical, social, psycho-emotional, spiritual, financial and cognitive aspects)
5. Looking back, if there was one thing that could improve your quality of life, what would that be?
6. Did the discussion miss out any important areas where your life had been affected by the illness and that you would like to share and discuss?

**Author Contribution**

YBC, GLL, RA, GSYP and HLW designed the study. YBC, RA, GSYP, and CCFW implemented the study. MYLO, GLL, HLW, CCFW, GKTF and YBC analyzed and interpreted the data. GLL, YBC and HLW wrote the first draft of the manuscript. All authors participated in the review and revision of the manuscript. All authors approved the submission.

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**Conflict of Interest**

The authors declare that they have no conflict of interest.

**References**

1. World Health Organization (2002) National Cancer Control Programs: Policies and Managerial Guidelines. World Health Organization, Geneva
2. Henoch I, Axelsson B, Bergman B (2010) The Assessment of Quality of life at the End of Life (AQEL) questionnaire: a brief but comprehensive instrument for use in patients with cancer in palliative care. Qual of Life Res 19:739-750.
3. Lyons KD, Bakitas M, Hegel MT, Hanscom B, Hull J, Ahles TA (2009) Reliability and validity of the Functional Assessment of Chronic Illness Therapy-Palliative Care (FACIT-Pal) Scale. J Pain Symptom Manage 37:23-32.
4. Cohen SR, Mount BM, Bruera E, Provost M., Rowe J., Tong K. (1997) Validity of the McGill Quality of Life Questionnaire in the palliative care setting: a multi-centre Canadian study demonstrating the importance of the existential domain. Palliat Med 11:3-20.
5. Sterkenburg CA, King B, Woodward CA (1996) A reliability and validity study of the McMaster Quality of Life Scale (MQLS) for a palliative population. J Palliat Care 12:18-25.
6. Byock IR, Merriman MP (1998) Measuring quality of life for patients with terminal illness: the Missoula-VITAS quality of life index. Palliat Med 12:231-244.
7. Steinhauser KE, Clipp EC, Bosworth HB, Mcneilly M, Christakis NA, Voils CI, Tulsky JA (2004) Measuring quality of life at the end of life: validation of the QUAL-E. Palliat Support Care 2:3-14.
8. Cella DF (1995). Measuring quality of life in palliative care. Seminars in Oncology 22(2 Suppl. 3):73-81.
9. Patrick DL, Burke LS, Gwaltney CJ, Leidy NK, Martin ML, Molsen E, Ring L (2011) Content validity - Establishing and reporting the evidence in newly developed patient-reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO good research practices task force report: Part 1 - Eliciting concepts for a new PRO instrument. Value Health 14:967-977.
10. Patrick DL, Burke LS, Gwaltney CJ, Leidy NK, Martin ML, Molsen E, Ring L (2011) Content validity - Establishing and reporting the evidence in newly developed patient-reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO good research practices task force report: Part 2 – Assessing respondent understanding. Value Health 14:978-988.
11. Lo RSK, Woo J, Zhoc KCH, Li CYP, Yeo W, Johnson P, Mak Y, Lee J (2001) Cross-cultural validation of the McGill quality of life questionnaire in Hong Kong Chinese. Palliat Med 15:387-397.
12. Tsujikawa MA, Yokoyama KB, Urakawa KC, Onishi KA (2009) Reliability and validity of Japanese version of the McGill Quality of Life Questionnaire assessed by application in palliative care wards. Palliat Med 23:659-664.
13. Kim KU, Yoon S-J, Lee J, Ahn H-S, Park H-J, Lee S-I, Jo M-W (2006) Validation of the Korean version of the McMaster Quality of Life Scale in terminal cancer patients. J Palliat Care 22:40-45.
14. Lasch KE, Marquis P, Vigneux M, Abetz L, Arnould B, Bayliss M, Crawford B, Rosa K (2010) Pro-development: Rigorous qualitative research as the crucial foundation. Quality Life Res 19:1087-1096.
15. Denzin NK, Lincoln YS (2005) Paradigms and perspectives in contention. In: Denzin NK & Lincoln YS (eds) The SAGE handbook of qualitative research*,* 3rd edn. Sage, Thousand Oaks, pp 153–189.
16. Patton MQ (2002) Qualitative research and evaluation methods, 3rd edn. Sage, Thousand Oaks.
17. Braun V, Clarke V (2006) Using thematic analysis in psychology. Qual Res Psychol 3:77-101.
18. Charmaz K (2006) Constructing grounded theory: A practical guide through qualitative analysis*.* Sage, London.
19. Edwards A, Pang N, Shiu V, Chan C. (2010) The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. Palliat Med 24:753-770
20. Mehta A, Chan LS (2008) Understanding of the concept of “total pain”: A prerequisite for pain control. J Hosp Palliat Nurs 10:26-32.
21. Maciocia G. (2015) The Foundations of Chinese Medicine: A Comprehensive Text. Amsterdam: Elsevier.
22. Chan CLW, Palley HA (2005) The use of traditional Chinese culture values in social work health care related interventions in Hong Kong. Health & Social Work 30:76-79.
23. Fukuhara S, Ware Jr JE, Kosinski M, Gandek B (1998) Psychometric and clinical tests of validity of the Japanese SF-36 health survey. J Clin Epidemiol 51:1045-1053.
24. Thumboo J, Fong KY, Machin D, Chan SP, Leong KH, Feng PH, Thio ST, Boey ML (2001) A community-based study of scaling assumptions and construct validity of the English (UK) and Chinese (HK) SF-36 in Singapore. Quality Life Res 10:175-188.
25. Tseng HM, Lu JFR, Gandek B (2003) Cultural issues in using the SF-36 health survey in Asia: Results from Taiwan. Health Qual Life Outcomes 1:72-80.
26. Lee GL, Fan GKT, Chan SWC (2015) Validation of Chinese and English versions of the Holistic Well-being Scale in patients with cancer. Support Care Cancer. Article first published online on Apr 17 2015, DOI 10.1007/s00520-015-2736-3.
27. Ow R, Katz D (1999) Family secrets and the disclosure of distressful information in Chinese families. Fam Soc 80:620-628.
28. Kreling B, Selsky C, Perret-Gentil P, Huerta EE, Mandelblatt JS, and For the Latin American Cancer Research Coalition (2010) “The worst thing about hospice is that they talk about death”: Contrasting hospice decisions and experience among immigrant Central and South American Latinos to US-born White, Non-Latino cancer caregivers. Palliat Med 24:427-434.
29. Lee GL, Ow R, Akhileswaran R, Goh CR (2013) Exploring the experience of dignified palliative care in patients with advanced cancer and families: A feasibility study in Singapore. Prog Palliat Care 21:131-139.
30. Ho DY (1995) Selfhood and identity in Confucianism, Taoism, Buddhism, and Hinduism: Contrasts with the West. J Theory Soc Behav 25:115-139
31. Wong PTP, Reker GT, Gesser G (1994) Death attitude profile-revised: A multidimensional measure of attitudes towards death. In: RA Neimeyer (ed) Death anxiety handbook: Research, instrumentation, and application. Taylor & Francis, Philadelphia, pp 121-148.
32. World Health Organization (2013) Global Health Observatory Data Repository - Health financing: Health expenditure ratios by country. [http://apps.who.int/gho/data/node.main.75. Accessed 13 March 2014](http://apps.who.int/gho/data/node.main.75.%20Accessed%2013%20March%202014).

|  |  |  |
| --- | --- | --- |
| Table 1. Demographics of participants (n=46) | | |
| **Participant characteristics** | **N** | **%** |
| **Age (years)** |  |  |
| *25-40* | *2* | *4.3* |
| *41-55* | *15* | *32.6* |
| *56-70* | *19* | *41.3* |
| *>70* | *10* | *21.7* |
| *Mean (SD)* | *59 (12)* | |
| **Sex** |  |  |
| *Male* | *22* | *47.8* |
| *Female* | *24* | *52.2* |
| **Marital status** |  |  |
| *Married* | *30* | *65.2* |
| *Single* | *9* | *19.6* |
| *Divorced/Separated* | *5* | *10.9* |
| *Widowed* | *2* | *4.3* |
| **Religion** |  |  |
| *Buddhist* | *21* | *45.7* |
| *Catholic* | *2* | *4.3* |
| *Christian* | *9* | *19.6* |
| *Free-thinker* | *8* | *17.4* |
| *Taoism* | *6* | *13.0* |
| **Education** |  |  |
| *No formal education* | *3* | *6.5* |
| *Primary School* | *11* | *23.9* |
| *GCE "N" or "O" Levels* | *17* | *37.0* |
| *GCE "A" Levels* | *4* | *8.7* |
| *Post-Secondary*  *Unknown* | *10*  *1* | *21.7*  *2.2* |
| **Years since cancer diagnosis** |  |  |
| *<2* | *13* | *28.3* |
| *2-5* | *16* | *34.8* |
| *6-10* | *11* | *23.9* |
| *>10* | *6* | *13.0* |
| **Primary Cancer Diagnosis** |  |  |
| *Breast* | *19* | *41.3* |
| *Colorectal* | *7* | *15.2* |
| *Liver* | *3* | *6.5* |
| *Lung* | *6* | *13.0* |
| *Others\** | *11* | *23.9* |
| **Patient’s ECOG status** |  |  |
| *0* | *16* | *34.8* |
| *1* | *20* | *43.5* |
| *2* | *7* | *15.2* |
| *3* | *3* | *6.5* |
| *4* | *0* | *0.0* |

*\* This includes 2 cases each for prostate and renal, and 1 case each for alveolar rhabdomyo sarcoma, tongue, cholangio, esophagus, gastric, thymic and uterus.*

Table 2. Major HRQoL domain, sub-domain, themes and sub-themes

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Domain** | **Sub-domain** | **Theme** | **Sub-theme** | **Sub-sub-theme** | **Concept addressed by the seven extant instruments** |
| PAIN AND SUFFERING |  | Physical pain and suffering  Mental pain and suffering  Existential pain and suffering  Welding pain and suffering syndrome | General pain and suffering  Pain intensity  Treatment-related pain  and suffering  Pain as a mental health issue  Mental suffering  Meaning of suffering | Living with suffering  Ending with death  Meaningless  Changes with different reference point | [A, B, E]  [A, E] |
| SOCIAL HEALTH | Family Relations | Support  Quality of Relationship | Presence of support    Absence of support  Positive  Negative  Change in family  relationship | Emotional support  Financial support  Health-related support (e.g. diet management)  Instrumental support  Psychosocial support  Spiritual support  Spousal support  No truthful concern  Husband filed for divorce  Feeling contented  Feeling motivated  Feeling loved  Feeling helped  Handling undesirable reactions  Irritated by the reminder of patient role  Presence of secrecy  To give up caregiver role  Adjustment in family activities  Stronger extended family ties  Stronger family bonds | [A, B, G]    [B]  [B]  [B]  [B, C]  [B]  [B]  [B, G]  [E]  [F] |
|  | Social Relations | Support  Quality of Relationship | Presence of support  Absence of support  Positive  Negative | Emotional support  Employment support  Health-related support  Instrumental support  Psychosocial support  Spiritual support  Lack of care and concern  Reduced social contacts  Feeling loved  Feeling closer  More reciprocal relationship  Handling undesirable reactions  Adjustment in social activities  Self-isolation  Presence of secrecy | [B, D]  [A, B, D, G]  [B, E]  [B]  [C]  [F]  [C] |
|  | Healthcare Relations | Support  Quality of Relationship | Presence of support  Absence of support  Positive  Negative  Neutral | Emotional support  Financial support  Informational support (e.g. treatment options)  Medical support (e.g. medical guidance)  No emotional support  Insufficient financial help  No information support  Trusting relationship  Reciprocal relationship  Opened relationship  Non-trusting relationship  One-way relationship  Closed relationship | [A, G]  [A]  [G]  [G] |
| MENTAL HEALTH | Cognitive Health | Cognition  Self-concept | Attention/ Concentration  Executive functioning  Learning  Positive self-concept  Negative self-concept | Easily tired  Shorter concentration span  Forgetfulness  Memory loss  Not registering information  Slower in processing information  Begin to read more  Fewer visits to library  Stopped writing  Be comfortable with a new self  Taking responsibility for self  A more easy-going personality  Feeling handicapped  Feeling like a lesser person  Feeling unimportant  Feeling useless | [A, E]  A, B]  [D, F]  [F] |
|  | Emotional Health | Emotion Associated with Illness | Acceptance (e.g. peace)  Anger  Anxiety & stress  Contentment  Emotionally not affected  Fear (e.g. scared, shocked)  Feeling nothing  Gratefulness  Happiness (cheerfulness)  Helplessness  Low moods (sad, depression)  Sense of normalcy (e.g. not treating one as sick)  Worry |  | [B, C, F, G]  [B, E]  [B, F]  [C]  [B, D]  [A, B, D, E]  [A, B, F]  [A, B, D, E, G] |
| SPIRITUAL HEALTH | Existential Well-Being | Death and Dying Concerns  Meaning of Death  Meaning of Illness  Meaning of Life | Acceptance (e.g. mentally prepared, no fear)  Resignation (e.g. no choice)  To be able die in sleep  No unfinished business  A natural path  A transition  An escape  An end to everything  Fate to fall sick  A growth opportunity  Contributing to others  Counting blessing  Finding happiness  Life regrets  Meaningless  Passive living |  | [F, G]  [F]  [B, E, F]  [B, C, G]  [A, B]  [D, G]  [A, B, C, D, E, F, G] |
| Religious Well-Being | Relationship with God/ Higher Power | Religious comfort  Religious support  Religious healing | Feeling closer to God/Higher Power  Feeling happy with God/Higher Power  Feeling supported  Receiving a miracle | [C]  [C] |
| FINANCIAL WELL-BEING |  | Financial Assistance  Financial Comfort  Financial Concern | Need for financial support  Receiving financial support  Affordable treatment plan  Constant source of income  Financially sound  No financial responsibility  Financial burden on family  Personal financial stress  Future financial concerns |  | [G] |
| PHYSICAL HEALTH |  | Physical Functioning | Functional self-care ability  Functional difficulty  Changes to daily living activities | Able to take care of daily living activities  Able to take charge of medical aspect  Able to take care of personal hygiene  Limited ability in daily living activities  Limited in locomotion  Limited ability in personal hygiene  Doing less what one used to do | [B, E, F]  [A, B, E] |

[A] indicates a concept was addressed in AQEL; [B] indicates a concept was addressed in FACIT-Pal (Version 4); [C] indicates a concept was addressed in FACIT-Sp-Ex (Version 4); [D] indicates a concept was addressed in McGill QoL; [E] indicates a concept was addressed in McMaster QoL; [F] indicates a concept was addressed in Missoula-VITAS QoL; and [G] indicates a concept was addressed in QUAL-E. A concept could be addressed by an item at any of the domain, theme or sub-theme levels.

Table 3. Exemplars of perceived HRQoL of advanced cancer patients

|  |  |  |  |
| --- | --- | --- | --- |
| **Domain**   * ***Sub-domain*** | **Theme** | **Sub-theme**   * ***Sub-sub-theme*** | **Example of quote+** |
| Pain and suffering | Physical pain and suffering  Mental pain and suffering  Existential pain and suffering  Welding pain and suffering syndrome | Treatment-related pain and suffering  Pain as a mental health issue  Meaning of suffering | ‘It (drainage of fluid) was painful…so painful that the machine… stopped…he (doctor) stopped whatever he’s doing, and rushed over to give me an injection of pain killer. Then he inserted the needle once more…from the back…forcefully. Wah, it’s really painful.’ (E46)  ‘The pain is killing, no way to cure, only that morphine. I will feel much better after drinking [morphine]. That is the problem. Pain is very awfully bad, this cancer. The pain is killing and you feel like jumping down.’ (E5)  ‘You see, if a normal person suffers, it’s okay.…But once you are having your cancer and you have to suffer all your life, it’s meaningless.”’ (E45)  “It’s really miserable; I am living like a dead body. And chemotherapy is really not easy. Why this medication, when it is invented and supposed to cure people, it causes so much “*xing-ku*” (hardship) to people?’ (C33) |
| Social Health   * *Family Relations* | Support | Presence of support   * *Instrumental support* | ‘She (mother-in-law) helped me to fetch my elder one [and] my younger one [to school]. My husband would fetch them back after school.’ (E17) |
| Quality of relationship | Positive   * *Feeling contented*   Changes in the family relationship   * *Stronger extended family ties* | ‘Even though now that I am sick, my children and daughter-in-law still stay by my side. My sons will take turns to sleep next to me. They are afraid that I need to wake up to pee and might fall down.… I am contented, my children are very obedient.’ (C6)  ‘Last time, the relationship between our siblings was not really good. It’s not really bad, just that not contacting much. When I had this illness, the relationship between our siblings has been closer.’ (C38) |
| * *Social Relations* | Support | Presence of support   * *Employment support* | ‘Sometimes I only work [one hour] a day only… because boss knows that I cannot carry heavy things due to my poor strength… I will go back home to take a nap.’ (C29) |
| Quality of relationship | Negative   * *Secrecy* | ‘I’m not able to tell them the truth…. because [I] get so many very strange reaction from people who [I] think [I] know…[I] never know how they’re going to react. Business partners, [I am] so afraid they’ll stop giving [me] the business because they think that [I] might not last till tomorrow.’ (E42) |
| * *Healthcare* *relations* | Support | Presence of support   * *Medical support* | ‘They (medical team) will come and visit sometimes, so I don’t have to make so many trips down to the hospital.’ (C16) |
| Quality of relationship | Neutral | ‘They are following their work, following their job scope…There’s nothing good or bad to say about it.’ (C30) |
| Mental Health  - *Cognitive Health* | Cognition  Self-concept | Executive functioning   * *Slower in processing information*   Negative self-concept   * *Feeling like a lesser person* | ‘…when it comes to thinking and processing, even [doing] mathematics…[it] always takes a long time.’ (E17)    ‘Painful in the sense that…[I feel] like [I am] a lesser person already’ (E10) |
| * *Emotional Health* | Emotion associated with illness | Low moods | ‘…it is life threatening disease, so of course there are times when I will be a bit down’ (E34) |
| Spiritual  Health   * *Existential health* | Death and dying concerns  Meaning of death  Meaning of illness  Meaning of life | No unfinished business  An end to everything  A growth opportunity  Finding happiness | ‘I got to say my sorry and say my goodbyes So in a way I think that I’m lucky; I’m blessed in a way.’ (E34)  ‘The illness is dragging me, it’s costly and painful. The best is that it can be resolved quickly. There is no problem once dead because I know there is no cure for my illness.’ (C5)  ‘…today I have cancer, I **know** [emphasized tone] how to lead my life. …I still can settle things that I want to do. So, I felt that I can find back my happiness, discover how to lead my life.’ (C35)  ‘I try to live my everyday as happy as I can.’ (E36) |
| * *Religious health* | Relationship with God/Higher Power | Religious healing | ‘…after the healing, the prayer, that Saturday night I sleep very well. God was working on me. I feel it is a wonder.’ (E20) |
| Financial Well-being | Financial Assistance  Financial Comfort  Financial Concern | Need for financial support  Financially sound  Personal financial stress | ‘I feel that after I have this disease, having financial support is really important.’ (C32)  ‘I have CPF (central provident fund, which is a national saving scheme). It’s accumulated during my long periods of employment for almost for 30 over years.’ (C13)  ‘I am just afraid that I need to eat this kind of medication that is very expensive, that I can’t afford….If my Medisave (a national saving scheme to meet the healthcare needs) is used up and I need to eat it long term, what kind of solution will I have? There’s definitely no solution to this.’ (C9) |
| Physical Health | Physical Functioning | Function difficulty   * *Limited ability in personal hygiene care* | ‘My body is weak. Sometimes I don’t feel like getting up, wash up, brush my teeth.…sometimes my child has to assist me to toilet.’ (C33) |

+ The quotes were selected to illustrate and explain the theme and sub-theme.