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Patient-reported outcome measures for advanced cancer in China: A systematic review of cross-cultural adaptation and psychometric properties

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ABSTRACT

Background: The number of patients with advanced cancer in China is rapidly increasing. As services and policy evolve, it is essential to improve the quality of care by measuring outcomes of importance to patients and families by identifying patient-reported outcome measures (PROMs) for use with advanced cancer patients in China, and critically appraising their cross-cultural adaptation process and measurement properties.
Methods: A systematic review was conducted in accordance with COnsensus-based Standards for the selection of health status Measurement INstruments (COSMIN), with quality assessment using the Guidelines for the Process of Cross-Cultural Adaptation of Self-Report Measures and COSMIN quality criteria for measurement properties. MEDLINE, EMBASE, PsycINFO, CINAHL, CNKI and WanFang were systematically searched from inception to May 2019, updated to August 2022. Supplemental searches were conducted in grey literature databases, Google scholar and hand-searching of reference lists.
Results: From 10793 articles, 437 were selected for full-text review based on titles and abstracts. A total of 46 studies reporting 39 PROMs were retained. No articles were rated as "good quality" in more than four of the six stages of cross-cultural adaptation. At least half of the required information on psychometric properties was missing for each measure. Based on COSMIN, none identified PROMs were valid across all properties nor appropriate to use.
Conclusion: There is currently no contextually appropriate and psychometrically sound PROMs for advanced cancer patients in China. The psychometric literature suggest that adaptation of existing measures is the potential solution.
Policy summary: Developing outcome measures for advanced cancer patients in China is invaluable to improve audit, clinical services and assess the quality of care, for research purposes and secure funding. Future research in measures' development, refinement and cross-cultural adaptation in this field is urgently needed.

1. Background

China is the most populous nation in the world and is rapidly ageing. The 176 million elderly adults (aged 65 years or older) in China at the end of 2019 accounted for 13% of the total population [1]. The proportion of the population aged at least 60 years is projected to increase from 12.4% in 2010 to 28% in 2040 [2]. China had an estimated 4,292,000 new cancer cases and 2,814,000 cancer deaths in 2015 (and is the leading cause of death), representing 22% of all incident globally, 27% of global cancer deaths [3].

Advanced cancer brings psychological, socioeconomic, physical and spiritual concerns [4]. Palliative care enables patients and families to live well with progressive illness, improving their outcomes and saving costs [5–9]. Approximately 0.7% of hospitals in China offer palliative care, and only 10% of patients have access to palliative care [10]. It is essential to ensure that investment in access to palliative care is pursued with a focus on care quality. Quality care is person-centred with the multidimensional assessment of patients and families to identify their more burdensome symptoms and concerns [11] and is measurable by determining the change in patient health status [12]. Patient reported outcome measures (PROMs) are the instruments or tools to measure patient reported outcomes (PROs), which are directly reported by

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patients to measure their perception of their well-being and functional status [13]. Using PROMs facilitates a systematic and comprehensive approach to patient assessment and identifies problems, standardises practice and improves patient management using data directly from the patient and their families [14,15]. PROMs offer significant potential to improve comprehensive cancer care [16], especially in symptoms recognition [17,18]. There is growing interest in integrating patient-reported outcomes into routine oncology practice for symptom monitoring [19].

The cross-cultural adaptation refers to the process of reaching equivalence between the original and target versions of the PROMs for use in new languages [20]. It is significant to establish face and content validity of PROMs in order to promote effective communication and quality of care as illness and healthcare have different meaning in different cultures, religions and languages [21]. The ideal outcome measurement scale should be valid, reliable and responsive, facilitating the delivery of structured, quality palliative care, audit, research and evaluation [22]. A systematic review identified a small evidence base for palliative care in Greater China and the use of single domain measures [23]. However, it is unclear whether there are currently measures with sound psychometric properties recommended for use with advanced cancer patients in China.

This review aimed to systematically identify patient-centred measures for advanced cancer patients in China and critically appraise their measurement properties. The objectives are to 1) identify PROMs reported in the peer review literature that has been tested with advanced cancer patients in China; 2) appraise the development, cross-cultural adaptation and /or validation methods and findings of the reported PROMs.

2. Methods

This systematic review was performed in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [24], COSMIN [25–27] methodologies for systematic reviews of PROMs, Guidelines for the process of cross-cultural adaptation of self-report measures [28], and the Peer Review of Electronic Search Strategies (PRESS) Guidelines [29].

2.1. Search strategy

The six following electronic databases were systematically searched from inception to May 2019, updated in August 2022: MEDLINE, EMBASE, PsycINFO and CINAHL (English-language literature); CNKI and WanFang (Chinese literature).

Supplementary searches were conducted by hand searching reference lists, grey literature for policy and practice references [30] (OpenGery and Global Health), and Google Scholar [31,32]. Endnote was used to manage references.

The search strategy (Appendix 1) was in accordance with COSMIN [25–27] methodology for systematic reviews of PROMs. Search terms were adapted according to Terwee et al. [33] to ensure sensitive search filters for three constructs (1) patient-reported outcome measurement, (2) Chinese population, (3) advanced cancer. Terms within each group were combined with a Boolean 'OR' command and searched in a combination using a Boolean 'AND' command. Before commencing the searches, the strategies were reviewed and checked against the Peer Review of Electronic Search Strategies (PRESS) Guidelines [29], with advice from an information specialist.

2.2. Inclusion/ exclusion criteria

Inclusion criteria: i) Studies reporting on the development, validation and/or cross-cultural translation and revalidation of instruments measuring patient health status designed to be completed by patients with advanced cancer or a proxy. ii) Studies examining one or more measurement properties of an instrument in advanced adult cancer patients (stated to be at a terminal stage, Stage III or IV, or no longer responding to curative treatment) in China. iii) Studies published in English or Chinese. iv) Full-text articles.

Exclusion criteria: i) Studies only report PROM data without reporting measurement properties. ii) Studies of unstructured tools. iii) Studies on individuals with a non-cancer diagnosis or early-stage cancer diagnosis. iv) Editorials, reviews and conference abstracts.

2.3. Study selection

Following deduplication, search returns were initially titles and abstracts screened, and then full manuscripts of all studies were retrieved. The first reviewer (HL) screened these, with discussion on inclusion or exclusion decided where necessary with a second reviewer (PG). Discussions focussed on the exclusion of the overseas-born Chinese population and the early cancer stage. Discrepancies were resolved through discussion with the reach team and the consensuses were reached. The process is presented in a PRISMA flow diagram [34].

2.4. Data extraction

To assess the quality of cross-cultural adaptation (where relevant), the following information was extracted in each step of standardised process of cross-cultural adaptation described by Beaton et al.: stage I – forward translation, stage II – synthesis, stage III – backward translation, stage IV – expert committee review, stage V – pretesting and stage VI – submission [28]. Data on the following measurement properties were extracted: content validity, construct validity, internal consistency, test-retest reliability, responsiveness, floor and ceiling effect and interpretability based on Terwee et al. [35] Additional data were extracted where available, including age, gender, diagnosis, cancer stage, and completion time (Table 1).

2.5. Data synthesis

Tools were categorised by domain measured. The categories were adapted from Categories of End-of-Life Care and Recommended Measures Online Toolkit [36,37]. The following analyses were conducted. Cross-cultural adaption (CCA) process was evaluated based on the Guidelines for the Process of Cross-Cultural Adaptation of Self-Report Measures described by Beaton et al. [28] We assessed the quality of each stage of cross-cultural adaption with quality criteria adapted from Oliveira et al., which is the recommended methodologically evaluates the quality of each step of translation and cross-cultural adaptation, such as the number of translators required, adequate sample size, test-retest interval, etc [38]. (see Appendix 2).

Measurement properties were assessed against criteria based on Terwee et al. as follows (see Appendix 3) [35]. In addition, Content Validity Index (CVI), i.e. rating of item relevance by content experts [39]: threshold for validity $\geq$ 80%. Construct validity (for studies using classical test theory) threshold of comparative fit index (CFI) or Tucker-Lexis index (TLI) or comparable measure $>$ 0.95 or Root Mean Square Error of Approximation(RMSEA) $<$ 0.06 or Standardised Root Mean Residuals(SRMR) $<$ 0.08 [35].

Research ethics committee/ institutional review board approvals were not required as this was a systematic review of pre-existing evidence.

3. Results

3.1. Paper selection

A total of 10793 articles were identified (including 6964 found in May 2019, with an additional 3829 in February 2021). Full-text reviews were conducted for 437. A total of 46 studies were retained in the review

Table 1
Summary of included studies.

Study	Year	Place of study sites	Measure	No. of domains	No. of items	N	Age (Mean±SD, Range) years
Au et al. [41]	2011	Hong Kong	SCNS-SF34-C	5	34	348	53.74 ± 9.91, 27–81
Chen et al. [42]	2019	Mainland China	MDASI-GI-C	2	25	527	54.9 ± 11.2, 25–81
Cheng et al. [43]	2009	Hong Kong	MSAS	3	32	370	54.2 ± 11.9, 21–84
Chie et al. [44]	2010	Taiwan	EORTC QLQ-OES18	4	18	95	61 ± 12 for the off-treatment group 58 ± 12 for the on-treatment group
Chie et al. [45]	2010	Taiwan	EORTC QLQ-OV28	7	28	96	54 ± 12
Cui et al. [46]	2014	Mainland China	MQOL	4	17	531	45–60 years: 27.3% 60–74 years: 30.9% 75 years or older: 32.8%
Fu et al. [47]	2018	Mainland China	MSAS	3	32	359	53.69 ± 11.76,22–80
Ger et al. [48]	1999	Taiwan	BPI-T		0–10 numeric scales for item rating with 0 being 'no pain' and 10 being 'pain as bad as you can imagine'	534	55.1 ± 15.1, 12–80
Han et al. [49]	2017	Mainland China	SCNS-SF34-C	5	34	861	51.66 ± 12.75
He et al. [50]	2020	Mainland China	SAIL	3	25	258	48.34 ± 13.17, 18–76
Hu et al. [51]	2015	Mainland China	MQOL	4	16	126	48.9 ± 15.8, 20–84
Hu et al. [52]	2003	Taiwan	MQOL-Taiwan	4	16	64	47.77 ± 16.23
Huang et al. [53]	2017	Mainland China	MAX-PC	3	18	254	68.25 ± 7.61, 42–89
Lai et al. [54]	2009	Taiwan	MPI-sC	4	8	106	58.4 ± 15.4
Lam et al. [55]	2008	Hong Kong	MSAS	4	32	256	59.0 ± 9.78, 27–75
Lam et al. [55]	2008	Hong Kong	CMSAS	3	14	256	59.0 ± 9.78, 27–76
Lam et al. [56]	2015	Hong Kong	DCS	5	16	471	54.4 ± 9.9, 29–86
Lee et al. [57]	2017	Taiwan	UWQOL-C	2	13	211	59.4 ± 13.4, 30–91
Li et al. [58]	2016	Mainland China	C-HADS	2	14	641	54.6 ± 12.9, 18–88
Li et al. [40]	2013	Hong Kong, Taiwan	SCNS-SF34-C	5	34	360 (Hong Kong) 263 (Taiwan)	65.7 ± 11.1, 27–90 (Hong Kong) 58.4 ± 11.2, 23–82(Taiwan)
Li et al. [59]	2019	Mainland China	QONCS	5	28	612	56.17 ± 10.90, 22–80
Li et al. [60]	2007	Mainland China	MDASI-TCM		26	317	55.36 ± 11.82
Lin et al. [61]	2015	Taiwan	C-SpIRIT	5	33	260	55.89 ± 10.86, 20–65
Lou et al. [62]	2014	Mainland China	FACIT-AI	4	13	69	26–88
Luo et al. [63]	2014	Mainland China	EORTC QLQ-C15-PAL	10	15	187	59.1 ± 10.8
Luo et al. [64]	2015	Mainland China	EORTC QLQ-BM22	4	22	121	30–88 (58.00 ± 10.77)
Luo et al. [65]	2014	Mainland China	EORTC IN-PATSAT32	4	32	119	58, 23–88
Quan et al. [66]	2016	Mainland China	QLASTCM-Ga		43	240	59.3 ± 11.7, 27–92
Sun et al. [67]	2020	Mainland China	EORTC QLQ-SWB27	4	27	270	Female 61.64 ± 12.69 Male 57.79 ± 12.52

(*continued on next page*)

Table 1 (*continued*)

Study	Year	Place of study sites	Measure	No. of domains	No. of items	N	Age (Mean±SD, Range) years
Tang et al. [68]	2017	Taiwan	SWBS–M	2	20	243	58.6 ± 15.21, 16–92
Tang et al. [69]	2021	Mainland China	DADDS-C	2	15	256	50.73 ± 11.35
Tao et al. [70]	2021	Mainland China	Spiritual Coping Questionnaire	7 dimensions and 2 subscales	26	442	18–83 (52.03 ± 12.14)
Wang et al. [71]	1996	Mainland China	BPI-C		0–10 numeric scales for item rating with 0 being 'no pain' and 10 being 'pain as bad as you can imagine'	147	54 ± 18–86
Wang et al. [72]	2015	Mainland China	BFS-C	6	17	658	47.52 ± 8.23, 25–70
Wang et al. [73]	2019	Hong Kong	PNPC-sv	8	33	174	< 60 y = 109,62.66% > 60 y = 65, 37.4%
Wang et al. [74]	2004	Mainland China	MDASI-C	2	19	249	51, 18–77
Wong et al. [75]	2008	Hong Kong	ChPSQ-9	2	9	222	55.6 ± 12.37
Wong et al. [76]	2012	Hong Kong	FACT-C	5	36	536 (76.1% CRC, 23.9% Polyps)	63.9 ± 11.2
Wu et al. [77]	2020	Mainland China	CPPCN	6	36	198	57.6 ± 12.4, 22–82
Xia et al. [78]	2017	Mainland China	C-MiLS	5	25	251	44.4 ± 13.43
Yan et al. [79]	2022	Mainland China	ADAS	3	13	213	60–83 (65.43 ± 4.698)
Yin et al. [80]	2020	Mainland China	PTPQ	4	12	198	55.90 ± 10.82
Zhang et al. [81]	2016	Mainland China	EORTC QLQ-C15-PAL	10	15	243	59
Zhang et al. [82]	2022	Mainland China	Symptom assessment scale for patients with advanced cervical cancer undergoing concurrent chemoradiotherapy	6	23	171	26–78 (53.06 ± 9.65)
Zhang et al. [83]	2016	Mainland China	EORTC QLQ-BM22	4	22	221	60 ± 11.28, 29–88
Zhao et al. [84]	2000	Mainland China	EORTC QLQ-C30	3	30	191	42.2 ± 14.3, 18–78
Zheng et al. [85]	2021	Mainland China	Quality Care Questionnaire- Palliative Care	4	32	289	56.08 ± 11.91

ADAS: Advance Directive Attitude Survey; BFS-C: Chinese version of the Benefit Finding Scale; BPI: Brief Pain Inventory; ChPSQ-9: Nine-Item Chinese Patient Satisfaction Questionnaire; CPPCN: Cancer patients' palliative care needs questionnaire; DCS: Decisional Conflict Scale; EORTC: European Organisation for Research and Treatment of Cancer; FACT-C: Functional Assessment of Cancer Therapy – Colorectal; HADS: Hospital Anxiety and Depression Scale; MAX-PC: Chinese version of the Memorial Anxiety Scale for Prostate Cancer; MDASI: M. D. Anderson Symptom Inventory; MDASI-GI-C: Chinese Version of the M. D. Anderson Symptom Inventory Gastrointestinal Cancer Module; MiLS: Meaning in Life Scale; MPI-sC: Multidimensional Pain Inventory-Screening Chinese version; MQOL: McGill Quality of Life Questionnaire; MSAS: Memorial Symptom Assessment Scale; PNPC-sv: Problems and Needs in Palliative Care questionnaire-short version; PTPQ: Prognosis and Treatment Perception Questionnaire; QLASTCM-Ga: Quality of life assessment scale for gastric cancer patients; QLQ-BM22: Bone Metastases; QLQ-C15-PAL: Quality of Life in palliative cancer care patients; QLQ-C30: Quality of Life of Cancer Patients; QLQ-IN-PATSAT32: Satisfaction with In-Patient Cancer Care; QLQ-OES18: Oesophageal patients; QLQ-OV28: Ovarian patients; QLQ-SWB27: Spiritual Wellbeing; QONCS: Quality of Oncology Nursing Care Scale; SAIL: Spiritual Attitude and Involvement List; SCNS-SF34-C: Chinese version of the short-form Supportive Care Needs Survey questionnaire; SpIRIT: Spiritual Interests Related Illness Tool; SWBS–M: Spiritual Well-Being Scale-Mandarin version; TCM: Traditional Chinese medicine; UWQOL-C: University of Washington Quality of Life Chinese Version.

(see Fig. 1).

3.2. Summary of results

The retained 46 studies reported 39 PROMs (see Table 1 and more detailed information in the appendix 4): 30 studies conducted in Mainland China, eight in Hong Kong, and nine in Taiwan (one study [40] in both Hong Kong and Taiwan). All measures were developed for paper completion. Of the 15 PROMs developed for a single type of cancer, four were colorectal, three breast, two cervical, one oesophageal, one prostate, one ovarian, one gastric, one head and neck and one hepatocellular. With respect to disease stage of study participants, in 22 publications 100% were advanced, in 18 over 50% (50%−87.8%) participants were advanced, and six less than 50%. The number of domains measured ranged from 2 to 13, the number of items ranging from 8 to 36, with completion time from 2 to 30 min.

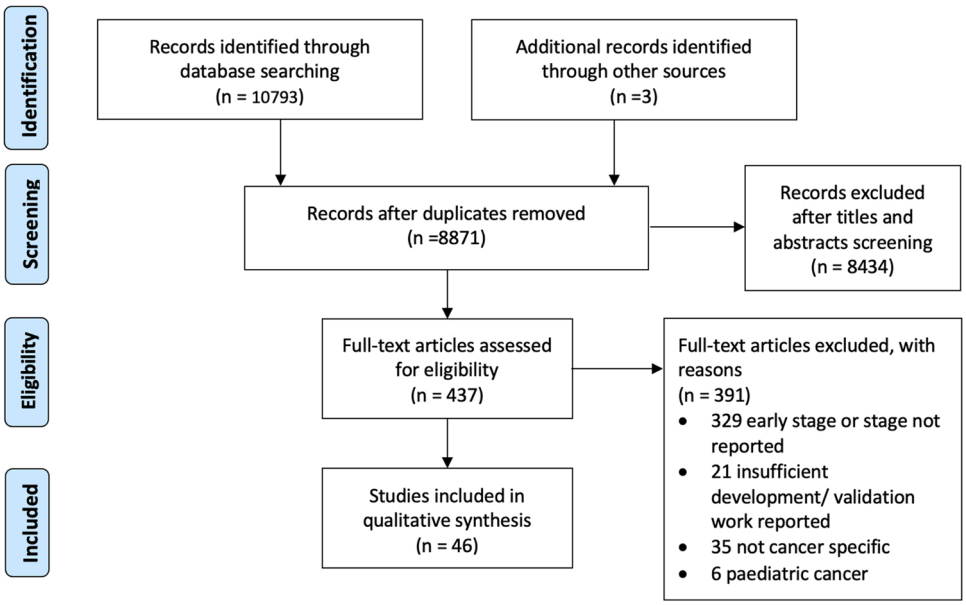

Fig. 1. Flow chat of studies selection.

3.3. PROM domains

Included PROMs were categorised in the Table 2 in accordance with Toolkit of Instruments to Measure End-of-Life Care [36,37]. We identified 18 measures of quality of life, six measures of physical symptoms, six measures of emotional and cognitive symptoms, five measures of spirituality, two measures of satisfaction and quality of care measure, one measure of continuity of care measure and one measure of advance care planning. No measure was found in the functional status category.

3.4. Quality of cross-cultural adaptation (CCA) process

Of the 46 studies included in this review, three reported PROM development in China, and 43 reported PROMs initially developed in other countries cross-culturally adapted to the Chinese population. (See Table 3) The quality of CCA was evaluated against Quality criteria [38] of the cross-cultural adaptation process and reported in Table 3. Of the 43 eligible articles, 33 (76.7%) reported some information on the translation and adaptation process, while 10 reported no details of the CCA process.

Table 2
Categorisation of the PROMs.

Domain (as recommended by the Toolkit [36,37])	PROMs
Quality of life	CPPCN, EORTC IN-PATSAT32, EORTC QLQ-BM22, EORTC QLQ-C15-PAL, EORTC QLQ-C30, EORTC QLQ-OES18, EORTC QLQ-OV28, MDASI-C, MDASI-GI-C, MDASI-TCM, UWQOL-C, FACIT-AI, FACT-C, MQOL (Mainland, Taiwan), PNPC-sv, QLASTCM-Ga, Quality Care Questionnaire-Palliative Care, SCNS-SF34-C (Mainland, HK, Taiwan)
Physical symptoms	MSAS-Ch, MSAS-SF, CMSAS, BPI, (Mainland, Taiwan), MPI-sC, Symptom assessment scale for patients with advanced cervical cancer undergoing concurrent chemoradiotherapy
Emotional and cognitive symptoms	BFS-C, C-HADS, DADDS-C, MAX-PC, PTPQ, SAIL
Continuity of care	DCS
Spirituality	C-MiLS, C-SpIRIT, QONCS, SCQ, SWBS–M
Satisfaction and quality of care	ChPSQ-9, Quality Care Questionnaire- Palliative Care
Functional status	–
Advance care planning	ADAS

Forward translation and back translation were the most tested stages, with 31 and 30 articles respectively completing these aspects of translation. In contrast, only one of the articles reported any reports or forms submitted to the developer of the instrument or central committee for appraisal. In the forward translation stage, 13 articles were rated as "+ " (translations conducted by two or more independent translators) and 18 as "?" (doubtful translation process) where translators' background or awareness status about the tool is different from the recommended, translation conducted by one translator mainly due to translation conducted by one translator. All the studies that completed the backward translation stage were rated as "?" (doubtful back-translation process, e.g. English is not the translators' first language, or they are aware of the instrument, back-translation conducted by one translator only). Expert committee review stage was described in 16 studies, of which 11 were all rate as "?" (doubtful expert committee review) because committee experts' roles were not clearly indicated, or the committee only reviewed part of documents generated in previous stages. Of the 21 articles that described pretesting, only three was rated as "+ ", while eight as "?" (doubtful design) where there is no mention of the number of subjects tested, target population not described) and ten studies did not meet the recommended sample size (> 30). No articles were rated as "+ " in more than four stages of the cross-cultural adaptation process.

See Appendix 2 for Quality criteria of the cross-cultural adaptation process.

3.5. Measurement properties

The properties are summarised in Table 4.

3.6. Validity

Content validity was tested and met the criteria for acceptability in 21/46 (45.7%) studies. CVI (content validity index) was used to determined content validity, which using ratings of item relevance by content experts.

Construct validity testing was carried out in 44/46 (95.6%) of the studies, reporting 39/39 (100%) PROMs. In all, 24/44 (54.5%) studies were rated as "+ ", 18/44 (40.9%) as "?", two (0.05%) as "-" and two (0.05%) as "0".

Table 3
Quality of cross-cultural adaptation process.

PROMs	Study	Place of study sites	Forward translation	Synthesis	Backward translation	Expert committee review	Pretesting	Submission
ADAS	Yan et al.[79]	Mainland China	?	?	?	?	?	0
BFS-C	Wang et al.[72]	Mainland China	?	0	?	0	0	0
BPI	Wang et al.[71]	Mainland China	?	0	?	0	0	0
	Ger et al.[48]	Taiwan	?	0	?	–	0	0
C-HADS	Li et al.[58][a]	Mainland China	?	+	?	0	0	0
C-SpIRIT	Lin et al.[61]	Taiwan	+	0	0	+	0	0
ChPSQ-9	Wong et al.[75]	Hong Kong	0	0	0	0	0	0
DADDS-C	Tang et al.[69]	Mainland China	?	?	?	0	?	0
DCS	Lam et al.[56]	Hong Kong	?	0	?	?	0	0
EORTC IN-PATSAT32	Luo et al.[65]	Mainland China	0	0	0	0	0	0
EORTC QLQ-BM22	Zhang et al.[83]	Mainland China	0	0	0	0	0	0
	Luo et al.[64]	Mainland China	?	0	?	0	0	0
EORTC QLQ-C15-PAL	Luo et al.[63]	Mainland China	0	0	0	0	0	0
	Zhang et al.[81][a]	Mainland China	+	+	?	0	–	0
EORTC QLQ-C30	Zhao et al.[84]	Mainland China	+	+	?	0	–	0
EORTC QLQ-OES18	Chie et al.[44]	Taiwan	0	0	0	0	?	0
EORTC QLQ-OV28	Chie et al.[45]	Taiwan	0	0	0	0	?	0
EORTC QLQ-SWB27	Sun et al.[67]	Mainland China	?	0	?	0	0	0
FACIT-AI	Lou et al.[62]	Mainland China	+	?	?	?	?	0
FACT-C	Wong et al.[76]	Hong Kong	0	0	0	0	0	0
MAX-PC	Huang et al.[53]	Mainland China	?	+	?	+	–	0
MDASI-C	Wang et al.[74]	Hong Kong	?	+	?	?	?	0
MDASI-GI-C	Chen et al.[42]	Mainland China	?	0	?	0	0	0
MDASI-TCM	Li et al.[60]	Mainland China	0	0	0	0	0	0
MPI-sC	Lai et al.[54]	Taiwan	?	0	?	0	0	0
MQOL	Cui et al.[46][b]	Mainland China	0	0	0	0	0	0
	Hu et al.[51]	Mainland China	?	0	?	0	0	0
	Hu et al.[52]	Taiwan	?	0	?	+	–	0
MSAS	Lam et al.[55]	Hong Kong	0	0	0	0	0	0
	Cheng et al.[43]	Hong Kong	?	0	?	?	–	0
	Lam et al.[55]	Hong Kong	?	0	?	0	0	0
	Fu et al.[47]	Mainland China	?	0	?	?	+	0
PNPC-sv	Wang et al.[73]	Hong Kong	+	+	?	0	–	0
PTPQ	Yin et al.[80]	Mainland China	+	+	?	0	–	0
QLASTCM-Ga	Quan et al.[66]	Mainland China	0	0	0	0	0	0
QONCS	Li et al.[59]	Mainland China	+	+	?	?	+	0
Quality Care Questionnaire-Palliative Care	Zheng et al.[82]	Mainland China	+	+	?	+	?	?
SAIL	He et al.[50]	Mainland China	+	+	?	+	+	0
SCNS-SF34-C	Au et al.[41]	Hong Kong	?	0	?	?	0	0
	Li et al.[40][a]	Hong Kong, Taiwan	+	+	?	?	–	0
	Han et al.[49]	Mainland China	+	+	?	?	–	0
SCQ	Tao et al.[70]	Mainland China	+	+	?	?	?	+
SWBS–M	Tang et al.[68]	Taiwan	0	0	0	0	0	0
UWQOL-C	Lee et al.[57]	Taiwan	+	+	?	0	–	0

[a] CCA process was reported in another publication: C-HADS [86], SCNS-SF34-C [49], EORTC QLQ-C15-PAL [84].
[b] The MQOL has been translated into Chinese, and its cross-cultural validity and reliability have been tested in Hong Kong and Taiwan [46], but no psychometric properties have been reported in Mainland China.

Table 4
Quality of measurement properties.

PROMs	Study	Content validity	Internal consistency	Construct validity	Test-retest reliability	Responsiveness	Floor and ceiling effects	Interpretability
ADAS	Yan et al. [79]	+	+	?	0	0	0	?
BFS-C	Wang et al.[72]	0	+	+	+	0	0	0
BPI-C	Wang et al.[71]	0	–	+	0	0	0	0
	Ger et al. [48]	0	+	+	–	0	0	?
C-HADS	Li et al. [58]	0	+	+	0	0	0	0
C-MiLS	Xia et al. [78]	+	+	+	0	0	0	0
C-SpIRIT	Lin et al. [61]	+	+	+	0	0	0	0
ChPSQ-9	Wong et al.[75]	0	+	+	0	0	0	0
CPPCN	Wu et al. [87]	+	+	?	0	0	0	0
DADDS-C	Tang et al.[69]	0	+	?	0	0	0	0
DCS	Lam et al. [56]	0	+	+	0	0	0	0
EORTC IN-PATSAT32	Luo et al. [65]	0	+	?	0	0	0	0
EORTC QLQ-BM22	Zhang et al.[83]	0	–	?	0	0	0	0
	Luo et al. [64]	0	+	?	0	0	0	0
EORTC QLQ-C15-PAL	Luo et al. [63]	0	–	?	0	0	0	0
	Zhang et al.[81]	0	+	–	0	0	0	0
EORTC QLQ-C30	Zhao et al.[84]	0	–	?	0	0	0	0
EORTC QLQ-OES18	Chie et al. [44]	0	–	0	0	0	?	0
EORTC QLQ-OV28	Chie et al. [45]	0	–	0	0	0	?	0
EORTC QLQ-SWB27	Sun et al. [88]	+	+	?	0	0	0	0
FACIT-AI	Lou et al. [62]	+	+	?	0	0	0	0
FACT-C	Wong et al.[76]	0	–	+	0	0	–	0
MAX-PC	Huang et al.[53]	+	+	+	+	0	0	0
MDASI-C	Wang et al.[74]	0	+	+	0	0	0	?
MDASI-GI-C	Chen et al.	0	+	?	0	0	0	0
MDASI-TCM	Li et al. [60]	0	+	+	+	0	?	0
MPI-sC	Lai et al. [54]	+	+	+	0	0	0	0
MQOL	Cui et al. [46]	0	0	+	0	0	0	?
	Hu et al. [51]	+	–	+	–	0	0	0
	Hu et al. [52]	+	–	+	0	0	0	0
MSAS	Lam et al. [55]	0	0	+	0	0	0	?
	Cheng et al.[43]	+	+	+	–	0	+	?
	Lam et al. [55]	0	0	+	0	0	0	?
	Fu et al. [47]	+	+	+	+	0	0	?
PNPC-sv	Wang et al.	+	+	?	0	0	0	0
PTPQ	Yin et al. [89]	+	+	?	0	0	0	0

(continued on next page)

Table 4 (*continued*)

PROMs	Study	Content validity	Internal consistency	Construct validity	Test-retest reliability	Responsiveness	Floor and ceiling effects	Interpretability
QLASTCM-Ga	Quan et al.[66]	+	+	+	+	–	0	0
QONCS	Li et al. [90]	+	+	?	+	0	0	0
Quality Care Questionnaire- Palliative Care	Zheng et al.[85]	+	+	?	+	0	0	0
SAIL	He et al. [91]	+	+	?	+	0	0	0
SCNS-SF34-C	Au et al. [41]	0	+	+	0	0	–	0
	Li et al. [40]	0	+	+	0	0	0	0
	Han et al. [49]	0	+	–	0	0	+	0
SCQ	Tao et al. [70]	+	+	?	+	0	0	0
SWBS–M	Tang et al.[68]	0	+	+	0	0	0	?
Symptom assessment scale for patients with advanced cervical cancer undergoing concurrent chemoradiotherapy	Zhang et al.[82]	+	+	?	+	0	0	0
UWQOL-C	Lee et al. [57]	+	–	+	+	0	0	0

3.7. Reliability

Internal consistency was tested in 44/46 (95.7%) studies, reporting 38/39 (97.4%) PROMs. Three of these had inadequate sample size (< 100) and seven reported Cronbach's alpha(s) < 0.7 in some subscales, which led to a "-" rating in all these ten studies.

Test-retest reliability testing was carried out in 14/46 (30.4%) of the studies. Of those three (21.4%) were rated as "-" due to ICC values < 0.7 in some subscales.

3.8. Responsiveness

Only one study [17] (2.17%) analysed responsiveness. Standardised response means (SRM) was calculated using a paired t-test to assess clinically meaningful changes.

3.9. Floor and ceiling effects

Floor and ceiling effects were tested in seven out of 46 (15.2%) studies. Of those two (28.6%) reported that $\leq$ 15% of the respondents achieved the highest or lowest possible scores. Three studies claimed floor and ceiling effects testing was conducted, but no detailed information was reported, therefore rating was "?".

Interpretability was tested in eight (17.4%) studies of those all were rated as "?" because Minimal important change (MIC) was not reported.

4. Discussion

A total of 46 studies, including 39 PROMs, were included in this review. None of the PROMs addressed all four domains of concern to patients with advanced cancer (i.e. physical, psychological, social and spiritual), and none were valid across all psychometric properties. No articles were rated "+ " in more than four stages of the cross-cultural adaptation process, demonstrating weak equivalence between the original language version and Chinese. The quality of measurement properties varied greatly. Content validity was tested and reported satisfaction in 21 (45.7%) studies. Internal consistency was tested in 44 (95.7%) studies, including 38 (97.4%). Responsiveness was only analysed in one study. Based on COSMIN, none identified PROMs were valid across all properties nor appropriate to use. Despite the incomplete information in the identified studies, results of this review suggest researchers and physicians working with advanced cancer patients in China have to choose the available measures without adequate psychometric properties, which risk unethical research and wasted resources [92].

None of the studies on measurement properties in this review achieved a rating of good quality in all characteristics. Internal consistency and construct validity were widely assessed in the included studies. In contrast, high proportion the information on properties per measure in each included study is missing and evidence is particularly limited in test-retest reliability, responsiveness, floor and ceiling effects and interpretability and greatly variations were observed in the methodological quality. Since accurate and reproducible measurements are prerequisites for an adequate instrument, acceptable validity and reliability is essential. There is a clear need of re-evaluation of some particular properties of measures with poor psychometric testing quality in future research. There is currently no ideal outcome measure for use in advanced cancer patients in China as the COSMIN recommends PROMs with evidence for sufficient content validity and at least low-quality evidence for sufficient internal consistency can be trusted [26,27,93].

Given that multidimensional unmet needs are associated with increased healthcare costs and increased distress, which can reduce survival, measures should ensure that all relevant dimensions are assessed efficiently [94,95]. For the quality-of-life scale, the only scale that met this standard was QLASTCM-Ga, which is specifically for gastric cancer patients in mainland China. There was no other quality of life scale that met standards for other cancer types in Hong Kong and Taiwan. Similarly, the only emotional and cognitive symptom scale that met standards was MAX-PC, which measures anxiety in prostate cancer patients in mainland China. MSAS met standards for use in the mainland and Hong Kong for evaluating physical symptoms, while MPI-sC met standards for use in Taiwan to measure pain in patients with advanced cancer. For scales measuring spirituality domain, C-MiLS met standards for use in mainland China and C-SpIRIT in Taiwan. Further research is needed to promote the use of multidimensional measures in China for clinical trials to measure treatment effects and in clinical practice to identify and prioritise problems, facilitate communications, monitor changes and treatment responses, staff training, and in clinical audit and governance.

When measuring non-tangible concepts, such as palliative care needs for advanced cancer patients, the methodological challenge in content validation is longstanding what matters and what should be measured.

Most of the included studies used CVI to establish face and content validity, which is the widely used method of quantifying content validity for multiitem scales [96]. An alternative method to establish face and content validity is qualitative methods, which were used in none of the included studies. Rigorous and transparent qualitative methodology is one of the most suitable methods for assessing content validity [97]. Qualitative analyses of the content validity of a measure assess not only the opinions of the measure under consideration but also the target population's conceptualisation intended to be assessed in order to have a better understanding of what matters to the participants and a firmer conclusion as to the content validity. Qualitative content validation can be established with the stakeholders who have first-hand and personal experience, which allow researchers to observe individuals with different background and how the construct of interest manifests itself in different individuals [98]. As there was no study reporting content validity qualitatively in advanced cancer patients in China, qualitative work amongst this population is needed to allow data from different perspectives and different methodologies.

5. Strengths and limitations

This systematic review summarised and critically appraised the psychometric measurement properties of existing PROMs used among advanced cancer patients in China, which provided the first robust and transparent evaluation of patient-reported measures for advanced cancer patients in China. The strengths of this systematic review are the comprehensive search strategy which found more than 10000 articles for potential inclusion and 46 papers were systematically appraised and compared, and the use of the COSMIN methodology.

This review also has several limitations. First, the search was restricted to databases in English or in Mainland China as the authors had no access to databases in Hong Kong and Taiwan. In addition, it was sometimes unclear if specific criteria on the COSMIN checklist were not performed or not reported on. Therefore, we had to use other evaluation criteria that were not suggested by COSMIN to assess the quality of measurement properties.

6. Conclusion

Collecting information using PROMs is a critical component of evaluating the complex needs of advanced cancer patients clinically and in research. As there are currently no contextually appropriate and psychometrically sound PROMs that measure the multidimensional concerns of advanced cancer patients in China, there is an urgent need for further high-quality methodological studies to properly evaluate and strengthen measurement properties. Developing outcome measures for advanced cancer patients in China is invaluable: to improve audit, clinical services and assess the quality of care, for research purposes and secure funding. A potential solution is adapting existing measures that have sound psychometric properties.

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Declaration of Competing Interest

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Appendix 1. Search strategy

1. ("Terminal Care" or "Palliative Care" or "Hospice Care" or "Terminally Ill Patients" or "Hospice Patients").hw. OR (palliati* or terminal or terminally ill* or end stage disease* or end of life or hospice* or advanced cancer or metasta* or late stage* or advanced stage* or advanced illness or incur* or end-stage).af.
2. (adenoma* or anticarcinogen* or blastoma* or cancer* or carcinogen* or carcinom* or carcinosarcoma* or chordoma* or germinoma* or gonadoblastoma* or hepatoblastoma* or hodgkin* or leukemi* or lymphangioma* or lymphangiomyoma* or lymphangiosarcoma* or lymphom* or malignan* or melanom* or meningioma* or mesenchymoma* or mesonephroma* or metasta* or neoplas* or neuroma* or nsclc or oncogen* or oncolog* or paraneoplastic or plasmacytoma* or precancerous or sarcoma* or teratocarcinoma* or teratoma* or tumor* or tumour*).ab,kw,ti.
3. (intermethod comparison or data collection method or validation study or feasibility study or pilot study or psychometry or reproducibility or observer variation or discriminant analysis or validity).hw. or (reproducib* or audit or psychometr* or clinimetr* or clinometr* or observer variation or reliab* or valid* or coefficient or internal consistency or (cronbach* and (alpha or alphas)) or item correlation or item correlations or item selection or item selections or item reduction or item reductions or agreement or precision or imprecision or precise values or test-retest or (test and retest) or (reliab* and (test or retest)) or stability or interrater or inter-rater or intrarater or intra-rater or intertester or inter-tester or intratester or intratester or interobeserver or inter-observer or intraobserver or intraobserver or intertechnician or inter-technician or intra-technician or intratechnician or interexaminer or inter-examiner or intraexaminer or intraexaminer or interassay or inter-assay or intraassay or intra-assay or interindividual or inter-individual or intraindividual or intra-individual or interparticipant or inter-participant or intraparticipant or intraparticipant or kappa or kappas or coefficient of variation or repeatab* or ((replicab* or repeated) and (measure or measures or findings or result or results or test or tests)) or generaliza* or generalisa* or concordance or (intraclass and correlation*) or discriminative or known group or factor analysis or factor analyses or factor structure or factor structures or dimensionality or subscale* or multitrait scaling analysis or multitrait scaling analyses or item discriminant or interscale correlation or interscale correlations or ((error or errors) and (measure* or correlat* or evaluat* or accuracy or accurate or precision or mean)) or individual variability or interval variability or rate variability or variability analysis or (uncertainty and (measurement or measuring)) or standard error of measurement or sensitiv* or responsive* or (limit and detection) or minimal detectable concentration or interpretab* or (small* and (real or detectable) and (change or difference)) or meaningful change or minimal important change or minimal important difference or minimally important change or minimally important difference or minimal detectable change or minimal detectable difference or minimally detectable change or minimally detectable difference or minimal real change or minimal real difference or minimally real change or minimally real difference or ceiling effect or floor effect or item response model or irt or rasch or differential item functioning or dif or computer adaptive testing or item bank or cross-cultural equivalence).ab,kw,ti.

4. (China or Chinese or Mandarin or Cantonese).ab,kw,ti.
5. (addresses OR biography OR case reports OR comment OR directory OR editorial OR festschrift OR interview OR lectures OR legal cases OR legislation OR letter OR news OR newspaper article OR patient education handout OR popular works OR congresses OR consensus development conference OR consensus development conference, nih OR practice guideline).pt. NOT (animals NOT humans).hw.
6. 1 AND 2 AND 3 AND 4
7. 6 NOT 5

Appendix 2. Quality criteria of the cross-cultural adaptation process

Stage	Rating	Quality criteria
I: Forward translation	+	Translations conducted by two or more independent translators
	?	Doubtful translation process (e.g. translators' background or awareness status about the tool are different from the recommended, translation conducted by one translator)
	−	Translation conducted by two non-independent translators
	0	No information on the forward translation process
II: Synthesis	+	Synthesis conducted by the same two or more translators from stage I
	?	Doubtful synthesis process (e.g. different translators or professionals from stage I)
	0	No information on the synthesis process
III: Back-translation	+	Back-translation made by two or more independent translators for whom English is the first language and who are naive to the instrument
	?	Doubtful back-translation process (e.g. English is not the translators' first language, or they are aware of the instrument, back-translation conducted by one translator only)
	−	Back-translation made by two non-independent translators
	0	No information on back-translation process
IV: Expert committee review	+	An expert committee is reported, and participants' roles clearly indicated. The committee reviews all documents
	?	Doubtful expert committee review (e.g. there is no mention of participants' roles)
	−	The committee reviews only one or some documents
	0	No information on expert committee
V: Pretesting	+	Pre-test was conducted in 30 or more subjects from the target population
	?	Doubtful design (e.g. there is no mention of the number of subjects tested, target population not described)
	−	Pre-test was conducted in less than 30 subjects
	0	No information on the pre-test
VI: Submission	+	All reports and forms were submitted to the developer of the instrument or central committee for appraisal
	?	Doubtful submission process (e.g. the reports and forms were received by others instead of the developer of the instrument or central committee)
	0	No information on submission process

Appendix 3. Quality criteria for measurement properties of health status questionnaires

Property	Definition	Quality criteria
1. Content validity	The extent to which the domain of interest is comprehensively sampled by the items in the questionnaire	+ A clear description is provided of the measurement aim, the target population, the concepts that are being measured, and the item selection AND target population and (investigators OR experts) were involved in item selection; ? A clear description of above-mentioned aspects is lacking OR only target population involved OR doubtful design or method; - No target population involvement; 0 No information found on target population involvement.
2. Internal consistency	The extent to which items in a (sub)scale are intercorrelated, thus measuring the same construct	+ Factor analyses performed on adequate sample size (7 * # items and ≥100) AND Cronbach's alpha(s) calculated per dimension AND Cronbach's alpha(s) between 0.70 and 0.95; ? No factor analysis OR doubtful design or method; − Cronbach's alpha(s) < 0.70 or > 0.95, despite adequate design and method; 0 No information found on internal consistency.
3. Construct validity	The extent to which scores on a particular questionnaire relate to other measures in a manner that is consistent with theoretically derived hypotheses concerning the concepts that are being measured	+ Specific hypotheses were formulated AND at least 75% of the results are in accordance with these hypotheses; ? Doubtful design or method (e.g., no hypotheses); − Less than 75% of hypotheses were confirmed, despite adequate design and methods; 0 No information found on construct validity.
4. Reliability	The proportion of the total variance in the measurements which is due to "true" differences	+ ICC or weighted Kappa ≥ 0.70; ? Doubtful design or method (e.g., time interval not mentioned); - ICC or weighted Kappa < 0.70, despite adequate design and method; 0 No information found on reliability.
5. Responsiveness	The ability of a questionnaire to detect clinically important changes over time	+ SDC or SDC < MIC OR MIC outside the LOA OR RR > 1.96 OR AUC ≥ 0.70; ? Doubtful design or method; − SDC or SDC ≥ MIC OR MIC equals or inside LOA OR RR ≤ 1.96 OR AUC < 0.70, despite adequate design and methods; 0 No information found on responsiveness.
6. Floor and ceiling effects	The number of respondents who achieved the lowest or highest possible score	+ ≤15% of the respondents achieved the highest or lowest possible scores; ? Doubtful design or method;

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Property	Definition	Quality criteria
7. Interpretability	The degree to which one can assign qualitative meaning to quantitative scores	− >15% of the respondents achieved the highest or lowest possible scores, despite adequate design and methods; 0 No information found on interpretation. + Mean and SD scores presented of at least four relevant subgroups of patients and MIC defined; ? Doubtful design or method OR less than four subgroups OR no MIC defined; 0 No information found on interpretation.

MIC = minimal important change; SDC = smallest detectable change; LOA = limits of agreement; ICC = Intraclass correlation coefficient; SD, standard deviation. + = positive rating; ? = indeterminate rating; − = negative rating; 0 = no information available.

Appendix 4. Summary of included studies

Study	Year	Place of study sites	Measure	No. of domains	No. of items	Completion time (min)	N	Age (Mean±SD, Range) years	Gender % female	Diagnosis	Cancer stage
Au et al. [41]	2011	Hong Kong	SCNS-SF34-C	5 (physical and daily living needs, psychological needs, patient care and support needs, health systems and information needs, sexuality needs)	34	10	348	53.74 ± 9.91, 27–81	100%	Breast cancer	43.4% advanced stages (III or IV)
Chen et al. [42]	2019	Mainland China	MDASI-GI-C	2 (symptom severity and interference subscales)	25	20–30	527	54.9 ± 11.2, 25–81	37.0%	Gastric 151 (28.7%) Colon 126 (23.9%) Rectal 138 (26.2%) Hepatobiliary 65 (12.3%) Pancreatic 25 (4.7%) Esophageal 22 (4.2%)	Stage I 0 Stage II 25(4.7%) Stage III 112 (21.3%) Stage IV 390 (74.0%)
Cheng et al. [43]	2009	Hong Kong	MSAS	3 (physical symptom subscale score, psychological symptom subscale score, global distress index)	32		370	54.2 ± 11.9, 21–84	52.20%	22% head and neck cancer 22% breast cancer 21% colorectal cancer	Stage I= 11.6% Stage II= 21.1% Stage III= 28.4% Stage IV= 34.6% unknown= 4.3%
Chie et al. [44]	2010	Taiwan	EORTC QLQ-OES18	4 (dysphagia, eating problems, reflux, pain)	18		95	61 ± 12 for the off-treatment group 58 ± 12 for the on-treatment group		Oesophageal cancer	Most patients were in advanced (III or IV) stages at diagnosis
Chie et al. [45]	2010	Taiwan	EORTC QLQ-OV28	7 (abdominal/ gastrointestinal symptoms, peripheral neuropathy, other chemotherapy side effects, hormonal/ menopausal, body image, attitude to disease and treatment, and sexual function)	28		96	54 ± 12	100%	Ovarian cancer	Most patients were in advanced (III or IV) stages at diagnosis
Cui et al. [46]	2014	Mainland China	MQOL	4 (physical, psychological, existential, support)	17		531	45–60 years: 27.3% 60–74 years: 30.9% 75 years or older: 32.8%	44.10%	Cancer	Stage IV
Fu et al. [47]	2018	Mainland China	MSAS	3 (physical symptom, psychological symptom, global distress)	32	5	359	53.69 ± 11.76,22–80	47.40%	29.0% Colorecta cancer 27.9% Gastric cancer 20.6% Breast cancer 13.6% Lung cancer 8.9% Others	Stage I= 1.7% Stage II= 5.6% Stage III= 9.2% Stage IV= 78.6% Unknown= 5.0%
Ger et al. [48]	1999	Taiwan	BPI-T		0–10 numeric scales for item rating with 0 being 'no pain' and 10 being 'pain as		534	55.1 ± 15.1, 12–80	36%	18% lung cancer 11% colon and rectum cancer 9% liver cancer 8% stomach cancer 7% breast cancer 6% uterus cervix cancer 41% others	61% advanced

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Study	Year	Place of study sites	Measure	No. of domains	No. of items	Completion time (min)	N	Age (Mean±SD, Range) years	Gender % female	Diagnosis	Cancer stage
					bad as you can imagine'						
Han et al. [49]	2017	Mainland China	SCNS-SF34-C	5 (physical and daily living needs, psychological needs, patient care and support needs, health systems and information needs, sexuality needs)	34		861	51.66 ± 12.75	43.30%	25.9% gastrointestinal tract cancer 23.7% nasopharynx cancer	71.2% advanced
He et al. [50]	2020	Mainland China	SAIL	3 (connectedness with oneself, connectedness with the environment, connectedness with the transcendent)	25		258	48.34 ± 13.17, 18–76	37.6%	solid tumours, 213 (82.6%)	Stage IV= 188, 72.9%
Hu et al. [51]	2015	Mainland China	MQOL	4 (physical, psychological, existential, and support)	16		126	48.9 ± 15.8, 20–84	44.40%	41.3% Thoracic cancer 25.4% Digestive cancer 7.9% Head and neck cancer 17.5% Genitourinary cancer 7.9% Others	Stage I= 4.8% Stage II= 19.5% Stage III= 24.3% Stage IV= 39.7% Undiagnosed= 11.7%
Hu et al. [52]	2003	Taiwan	MQOL-Taiwan	4 (physical, psychological, existential, and support)	16	30	64	47.77 ± 16.23	37.50%	39.1% haematological cancer 18.8% gastrointestinal tract cancer 15.6% lung cancer 6.3% gynaecological organs cancer	
Huang et al. [53]	2017	Mainland China	MAX-PC	3 (general prostate cancer anxiety, anxiety related to prostate-specific antigen testing, fear of recurrence)	18		254	68.25 ± 7.61, 42–89	0%	Prostate Cancer	22.4% locally advanced 33.8% advanced
Lai et al. [54]	2009	Taiwan	MPI-sC	4 (pain severity, pain interference with life activities, affective distress, life control)	8		106	58.4 ± 15.4	46.20%	Breast cancer Lung cancer Head and neck cancer Gastrointestinal cancer	advanced cancer
Lam et al. [55]	2008	Hong Kong	MSAS	4 (global distress index, physical symptom distress score, psychological symptom distress score, total MSAS)	32	6	256	59.0 ± 9.78, 27–75	34%	Colorectal cancer	20% were undergoing palliative radiation therapy/ chemotherapy 20% were undergoing symptomatic care
Lam et al. [55]	2008	Hong Kong	CMSAS	3 (physical symptom, psychological symptom, total CMSAS)	14		256	59.0 ± 9.78, 27–76	34%	Colorectal cancer	20% were undergoing palliative radiation therapy/ chemotherapy 20% were undergoing symptomatic care
Lam et al. [56]	2015	Hong Kong	DCS	5 (informed, values clarity, support, uncertainty, effective decision)	16	5	471	54.4 ± 9.9, 29–86	100%	Breast cancer	Stage 0 = 24.0% Stage I= 25.5% Stage II= 22.9% Stage III= 10.3% Stage IV= 19.3%
Lee et al. [57]	2017	Taiwan	UWQOL-C	2 (physical function, social-emotional function)	13	2–4	211	59.4 ± 13.4, 30–91	7.60%	51.7% oral cavity cancer 48.3% laryngeal cancer	Stage I= 20.4% Stage II= 23.7% Stage III= 23.7% Stage IV= 32.2%
Li et al. [58]	2016	Mainland China	C-HADS	2 (anxiety, depression)	14		641	54.6 ± 12.9, 18–88	49.60%	10.9% Breast cancer 14.5% Ovarian and cervical cancer 23.7% Oesophageal and gastric cancer 13.4% Colorectal cancer 9.2% Liver cancer	Stage III= 56.8% Stage IV= 43.2%

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Study	Year	Place of study sites	Measure	No. of domains	No. of items	Completion time (min)	N	Age (Mean±SD, Range) years	Gender % female	Diagnosis	Cancer stage
										13.7% Lung cancer 11.9% Others	
Li et al. [40]	2013	Hong Kong, Taiwan	SCNS-SF34-C	5 (physical and daily living needs, psychological needs, patient care and support needs, health systems and information needs, sexuality needs)	34		360 (Hong Kong) 263 (Taiwan)	65.7 ± 11.1, 27–90 (Hong Kong) 58.4 ± 11.2, 23–82 (Taiwan)	36.9% (Hong Kong); 43% (Taiwan)	Colorectal cancer	81.2% do not receive active treatment
Li et al. [59]	2019	Mainland China	QONCS	5 (support and confirmation, spiritual care, belonging, value, respect)	28		612	56.17 ± 10.90, 22–80	297 (48.5%)	Lung cancer 108 (17.6%) Stomach cancer 76 (12.4%) colorectal cancer 73 (11.9%) oesophageal cancer 59 (9.6%) breast cancer 58 (9.5%) cervical cancer 51 (8.3%) liver cancer 48 (7.8%) lymphoma 21 (3.4%) bladder cancer 17 (2.8%) pancreatic cancer 15 (2.5%) endometrial cancer 14 (2.3%) nasopharyngeal cancer 13 (2.1%) ovarian cancer 12 (2.0%) prostate cancer 11 (1.8%) other cancers 36 (6.0%)	advanced
Li et al. [60]	2007	Mainland China	MDASI-TCM		26	5	317	55.36 ± 11.82		23.66% Lung cancer 20.82% Breast cancer 15.14% Colorectal cancer 12.93% Lymphoma	Stage I= 14.29% Stage II= 16.03% Stage III= 23.69% Stage IV= 45.99%
Lin et al. [61]	2015	Taiwan	C-SpIRIT	5 (related to beliefs/religion, positive attitudes toward life, love to/from others, seeking for the meaning of life, peaceful mind)	33	3–7	260	55.89 ± 10.86, 20–65	56.92%	24.62% breast cancer 23.85% head and neck cancer 11.92% oral cancer	Stages II and III= 23.85% Stage IV= 45.77%
Lou et al. [62]	2014	Mainland China	FACIT-AI	4 (daily life, upper oesophageal, the volume of ascitic fluid, ascitic complications)	13	3.03 ± 1.22 min	69	26–88	46 (66.7%)	Gastric cancer 16, ovarian cancer 12, liver cancer 12, bowel cancer 12, pancreatic cancer 5, lung cancer 4, breast cancer 2, peritoneal mesothelioma 2, Hodgkin lymphoma 1, unknown 3	advanced
Luo et al. [63]	2014	Mainland China	EORTC QLQ-C15-PAL	10 (physical functioning, emotional functioning, fatigue, pain, nausea and vomiting, dyspnoea, insomnia, appetite loss, constipation and one single-item QOL scale)	15		187	59.1 ± 10.8	57.20%	32.1% lung cancer 9.6% breast cancer 8.6%gastric cancer 5.3% Colorectal cancer	advanced
	2015	Mainland China	EORTC QLQ-BM22	2 symptom scales (painful sites and	22		121	30–88 (58.00 ± 10.77)	67/121	Lung 51(42.1), Breast 26(21.5),	advanced

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Study	Year	Place of study sites	Measure	No. of domains	No. of items	Completion time (min)	N	Age (Mean±SD, Range) years	Gender % female	Diagnosis	Cancer stage
Luo et al. [64]				pain characteristics) and 2 functional scales (functional interference and psychosocial aspects).						Gastrointestinal 6 (5.0), Kidney 2(1.7), Prostate 2(1.7), Bone marrow 1(0.8), Bladder 1(0.8), Other 29(24.0), missing 3 (2.5)	
Luo et al. [65]	2014	Mainland China	EORTC IN-PATSAT32	4(unity of the body and spirit, correspondence between man and universe, specific module, general module)	32		119	58, 23–88	56.30%	cancer	advanced
Quan et al. [66]	2016	Mainland China	QLASTCM-Ga		43		240	59.3 ± 11.7, 27–92	37.50%	gastric cancer	advanced
Sun et al. [67]	2020	Mainland China	EORTC QLQ-SWB27	4(existential, relationships with others, relationship with someone or something greater, relationship with self)	27	10	270	Female 61.64 ± 12.69 Male 57.79 ± 12.52	66.8%		advanced
Tang et al. [68]	2017	Taiwan	SWBS–M	2 (religious well-being, existential well-being)	20		243	58.6 ± 15.21, 16–92	44%	cancer	advanced
Tang et al. [69]	2021	Mainland China	DADDS-C	two domains: better relationship with healthcare providers, preparation for end of life	15		256	50.73 ± 11.35	226 (88.3%)	Breast 186 (72.7%), Lung 20 (7.8), Gastrointestinal 26 (10.2%), Others 24 (9.4%)	Stage III and IV
Tao et al. [70]	2021	Mainland China	Spiritual Coping Questionnaire	7 dimensions and 2 subscales: positive spiritual coping (person, society, environment, transcendent) and negative spiritual coping (person, society, transcendent)	26	5–15 min	442	18–83 (52.03 ± 12.14)	161/442	Lung cancer 135, Gastrointestinal cancer 147, Head and Neck cancer 47, Lymphoma 28, Reproductive System cancer 17, Breast cancer 14, Others 54	Stage III 137, Stage IV 305
Wang et al. [71]	1996	Mainland China	BPI-C		0–10 numeric scales for item rating with 0 being 'no pain' and 10 being 'pain as bad as you can imagine'		147	54 ± 18–86	42%	33% lung cancer 27% GI tract cancer 10% breast cancer 7% genitourinary cancer 4% gynaecological cancer 19% others	49.3% advanced
Wang et al. [72]	2015	Mainland China	BFS-C	6 (acceptance of life's imperfections, becoming more cognizant of the role of other people in one's life, and developing a sense of purpose in life)	17		658	47.52 ± 8.23, 25–70	100%	Breast cancer	Stage III= 33.7%
Wang et al. [73]	2019	Hong Kong	PNPC-sv	8 domains: daily activities (3 items), physical (9 items), autonomy (4 items), social (5 items), psychological (5 items), spiritual (4 items), financial (2	33	11	174	< 60 y = 109,62.66% > 60 y = 65, 37.4%	39.7%	Lung cancer 54 (31.0%) Nasopharynx cancer 30 (17.2%) Colorectal cancer 29 (16.7%) Gynaecological cancer 32 (18.4%) Liver cancer 5 (2.9%)	Stage III= 70 (40.2%) Stage IV= 104 (59.8%)

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Study	Year	Place of study sites	Measure	No. of domains	No. of items	Completion time (min)	N	Age (Mean±SD, Range) years	Gender % female	Diagnosis	Cancer stage
				items) and informational (1 item)						Breast cancer 4 (2.3%) Oesophageal cancer 3 (1.7%) Oral cancer 6 (3.4%) Others 11 (6.4%)	
Wang et al. [74]	2004	Mainland China	MDASI-C	2 (general symptom severity factor, gastrointestinal factor)	19	20	249	51, 18–77	54	25% Gastrointestinal cancer 24% Breast cancer 21% Lung cancer	Stage I= 21% Stage II = 29% Stage III= 29% Stage IV= 21%
Wong et al. [75]	2008	Hong Kong	ChPSQ-9	2 (doctor-related issues and nurse-related issues)	9		222	55.6 ± 12.37	18.50%	hepatocellular carcinoma	87% advanced
Wong et al. [76]	2012	Hong Kong	FACT-C	5 (physical well-being, social/ family well-being, emotional well-being, functional well-being, colorectal cancer subscale)	36		536 (76.1% CRC, 23.9% Polyps)	63.9 ± 11.2	41.80%	CRC, Polyps	Among patients diagnosed with CRC, 23.5% were currently undergoing adjuvant or palliative CRC treatment
Wu et al. [77]	2020	Mainland China	CPPCN	6 (physical needs, psychological needs, environmental needs, social support needs, disease-related knowledge needs and information needs)	36		198	57.6 ± 12.4, 22–82	37.0%	Lung cancer 45 ovarian cancer 14 pancreatic cancer 24 stomach cancer 29 bowel cancer 20 liver cancer 35 breast cancer 31	advanced
Xia et al. [78]	2017	Mainland China	C-MiLS	5(acceptance and adaptation, life perspective, self-control, relationship, purpose in life)	25	8–12	251	44.4 ± 13.43	54.20%	40.64% Breast cancer 22.71% Lung cancer 21.51% Gastric cancer 12.35% Colorectal cancer 2% Gynaecologic cancer 0.8% Nasopharyngeal cancer	Stage I= 9.16% Stage II = 16.73% Stage III= 35.86% Stage IV= 38.25%
Yan et al. [79]	2022	Mainland China	ADAS	3 (opportunity for treatment choices, effect of advance directives on the family, effect of an advance directive on treatment)	13	3–5 min	213	60–83 (65.43 ± 4.698)	111 (52%)	Cancer	Stage III (n = 156, 73.2%) Stage IV (n = 57, 26.8%)
Yin et al. [80]	2020	Mainland China	PTPQ	4 (understand the importance and help of the prognosis, evaluate the quality of the prognostic information provided by the doctor, treatment and prognostic information preferences, prognosis and end-of-life discussions)	12		198	55.90 ± 10.82	41.9%	lung cancer 44 (22.22%) gastric cancer 36 (18.18%) CRC 31 (15.66) oesophageal cancer 26 (13.13%) gynaecological cancer 33 (16.67%) others 28 (14.14%)	Stage III= 98 (49.49%) Stage IV= 100 (50.51%)
Zhang et al. [81]	2016	Mainland China	EORTC QLQ-C15-PAL	10 (physical functioning, emotional functioning, fatigue, pain, nausea and vomiting, dyspnoea, insomnia, appetite loss, constipation and one single-item qol scale)	15		243	59	56.20%	10.7% Gastric cancer 38.8% Lung cancer (7.1% Liver cancer 5.1% Rectal cancer 13.3% Breast cancer 3.6% Cervical cancer 2.6% Head and neck cancer 1.0% Brain neoplasm/ spinal cord neoplasm 1.5% Pancreatic cancer 1.5%	advanced

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Study	Year	Place of study sites	Measure	No. of domains	No. of items	Completion time (min)	N	Age (Mean±SD, Range) years	Gender % female	Diagnosis	Cancer stage
										Cholangiocarcinoma 14.8% Other	
Zhang et al. [82]	2022	Mainland China	Symptom assessment scale for patients with advanced cervical cancer undergoing concurrent chemoradiotherapy	6 domains: psychological symptom group (5 items), nutritional symptom group (4 items), intestinal symptom group (5 items), urinary system related symptom group (3 items), sexual symptom group (2 items), and somatic symptom group (4 items)	23		171	26–78 (53.06 ± 9.65)	100%	cervical cancer	Stage IIB-IVA
Zhang et al. [83]	2016	Mainland China	EORTC QLQ-BM22	4 (painful sites, pain characteristics, functional interference, psychosocial aspects)	22		221	60 ± 11.28, 29–88	55.20%	41.2% Lung cancer 19.9% Brest cancer 5.0% Gastrointestinal cancer 1.8% Renal cell cancer 4.1% Prostate cancer 0.9% Multiple myeloma cancer 5.4% Bladder cancer 19.4% Others	Stage IV
Zhao et al. [84]	2000	Mainland China	EORTC QLQ-C30	3 (global health, functional scales, symptom scales)	30		191	42.2 ± 14.3, 18–78	100%	2.3% Unknown gestational trophoblastic disease patients (n = 68), ovarian cancer patients (n = 105), and patients with other types of gynaecological cancer (n = 18).	Stage III= 40%
Zheng et al. [85]	2021	Mainland China	Quality Care Questionnaire-Palliative Care	4 (communication with medical staff, discussing the goals and plans of treatment and care, support and evaluation of overall care, continuity of care)	32	6–20 min	289	56.08 ± 11.91	129/289	Lung cancer 75, gastric cancer 27, colorectal cancer 28, liver cancer 13, breast cancer 48, gynaecological cancer 21, pancreatic cancer 35, others 42	Stage IV

ADAS: Advance Directive Attitude Survey; BFS-C: Chinese version of the Benefit Finding Scale; BPI: Brief Pain Inventory; ChPSQ-9: Nine-Item Chinese Patient Satisfaction Questionnaire; CPPCN: Cancer patients' palliative care needs questionnaire; DCS: Decisional Conflict Scale; EORTC: European Organisation for Research and Treatment of Cancer; FACT-C: Functional Assessment of Cancer Therapy – Colorectal; HADS: Hospital Anxiety and Depression Scale; MAX-PC: Chinese version of the Memorial Anxiety Scale for Prostate Cancer; MDASI: M. D. Anderson Symptom Inventory; MDASI-GI-C: Chinese Version of the M. D. Anderson Symptom Inventory Gastrointestinal Cancer Module; MiLS: Meaning in Life Scale; MPI-sC: Multidimensional Pain Inventory-Screening Chinese version; MQOL: McGill Quality of Life Questionnaire; MSAS: Memorial Symptom Assessment Scale; PNPC-sv: Problems and Needs in Palliative Care questionnaire-short version; PTPQ: Prognosis and Treatment Perception Questionnaire; QLASTCM-Ga: Quality of life assessment scale for gastric cancer patients; QLQ-BM22: Bone Metastases; QLQ-C15-PAL: Quality of Life in palliative cancer care patients; QLQ-C30: Quality of Life of Cancer Patients; QLQ-IN-PATSAT32: Satisfaction with In-Patient Cancer Care; QLQ-OES18: Oesophageal patients; QLQ-OV28: Ovarian patients; QLQ-SWB27: Spiritual Wellbeing; QONCS: Quality of Oncology Nursing Care Scale; SAIL: Spiritual Attitude and Involvement List; SCNS-SF34-C: Chinese version of the short-form Supportive Care Needs Survey questionnaire; SpIRIT: Spiritual Interests Related Illness Tool; SWBS–M: Spiritual Well-Being Scale-Mandarin version; TCM: Traditional Chinese medicine; UWQOL-C: University of Washington Quality of Life Chinese Version.

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