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ACCEPTED MANUSCRIPT

Cancer patient experience measures - an evidence review

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Abstract

Objectives: This research investigates the instruments currently available to measure the cancer patient experience of health care. An investigation of the number of instruments, the domains covered by the instruments, and the structure and psychometric performance of instruments is undertaken.

Methods: A narrative synthesis approach is used to gather evidence from multiple studies and explain the findings. Purposely broad search terms and strategy are used to capture studies with cancer patients at all stages of disease and across a range of cancer types and health care settings.

Results: The majority of identified instruments were originally designed for the oncology field. Twelve of the studies developed new cancer patient measures; eight studies adapted existing or utilised items from existing instruments, seven studies assessed the psychometric properties of existing instruments or assessed validated tools under different conditions (e.g. cross cultural adaptation). The number of instruments assessing cancer patient experience that have sound psychometric properties across items was found to be low. The properties least tested are test-

retest reliability, construct, convergent and discriminant validity, scale variability (floor/ceiling effects) and interpretability: *Conclusion:* This review examined ten years of research on the development of instruments to measure the cancer patient experience of health care. It found that research in this area is still in early stages of development. Further inquiry based development and validation of cancer patient experience measures is required to support improvements in cancer care based on the perspective of cancer patients.

Keywords

Cancer, Patient, Experience, Measures, Indicators

Introduction

Clinical oncology has taken a lead in patient centred care in an effort to better support the often lengthy and arduous cancer patient journey (i.e. diagnosis, treatment, care and ongoing management), as the care journey strongly influences cancer patients' psychological wellbeing and perceived quality of life.¹ What is less clear is the extent to which purpose designed, psychometrically sound measures are available to assess the cancer journey from the patient's perspective and provide additional confidence to health services in changing cancer care practices based on their results. Researchers suggest that establishing a valid set of patient reported measures reflects further progress towards improving the patient centredness of cancer care.²

Activity in healthcare quality assessment has grown since the 1960s with the improvement focus of many of the measures continuing to be defined from the perspectives of clinicians and health administrators.³ More recently, collecting and engaging with patient feedback with the aim of supporting care that is tailored to the requirements of patients is growing in importance. Whether or not these processes of measurement and reporting have caused a marked impact on health outcomes is not clear. Regardless, patient reported measures aimed at facilitating improvement efforts are now formally recognised as key contributors of healthcare quality, alongside safety and clinical effectiveness.⁴

The use of patient reported measures is often an attempt to identify the degree to which health care is ‘patient-centred’, the key features of which are defined as: identifying and respecting patient choices; informing and involving patients; involving patients in health care processes; treating patients with dignity; ensuring health care processes match patient needs; access to relevant health information; and continuity of care.⁵ To ensure translation of these features into care processes, patient experience data must be sufficiently and accurately captured. Until recently, patient experience and other complex subjective patient reported themes were considered beyond the scope of accurate measurement. However a growing body of evidence has now shown that aspects of care from the patient’s perspective can be measured in purpose designed and tested instruments, providing convenient numerical summaries of features of the healthcare journey that patients consider important.

Assessments of patient reported healthcare measures are undertaken in various ways by numerous groups, at different times in a patient's care process via a number of methods. The instruments often include measures from across various areas such as patient reported: preferences; experiences; outcomes; and/or satisfaction with care. Collecting and cross-referencing information across these domains provides a rich platform on which care might be transformed and more information provided on what is important to patients than would otherwise be available if each area was measured in isolation.⁶

When examining instruments that measure what matters to patients, one of the most important considerations is establishing the fidelity of the instrument. Numerous properties are tested to give confidence that instruments are measuring what they are designed to measure. These properties include: reliability (i.e. produces consistent results in repeated measurements of the same circumstance or event); validity (i.e. the measure is related to the dimension it is supposed to assess (i.e. face validity); whether it covers the whole dimension it is supposed to assess (i.e. content validity); and is it related to other measures evaluating the same dimension (i.e. construct validity).⁷

Aim

This work is part of a larger project investigating the cancer patient experience field overall.⁸ The aim of this inquiry is to investigate the instruments currently available to specifically measure the cancer patient experience of health care. An investigation of the number of instruments, the domains covered by the instruments, and the structure and psychometric performance of

instruments is conducted. The present work builds on a number of existing global reviews of instruments that measure cancer patient reported measures including patient satisfaction, experience and quality of life measures.^{9,10} This research specifically focuses on the body of advances reported in the most recent literature (>2005) on instruments designed to principally measure cancer patient experience to inform potential widespread adoption in cancer care settings.

Method

A narrative synthesis approach is used to gather evidence from multiple studies and explain the findings. This approach is most suited to diversity in evidence and allows investigators to draw a picture of the overall knowledge and practice of the area under investigation.¹¹ For the purpose of this review, cancer refers broadly to all types of cancer, except paediatric cancers. The patient experience is defined as *“the patient’s interpretation and evaluation of everything they see, feel and hear while receiving care from a health facility. Patient experience impacts the whole patient journey, from pre-care to clinical care to follow-up care and everything that happens in the ‘gaps’”*.¹²

Inclusion criteria for this review were primary studies targeting adult cancer patient populations (i.e. aged 18 years or older); published in English; were published between 2005 and April 2015; reported the development and/or psychometric evaluation or validation of cancer patient reported experience measures; or reported the validation of an existing cancer patient specific measure for use with a different population (e.g. cancer patient care experience measure translated for use with a

cancer patient population in another comparable country). Exclusion criteria included reviews, editorials, commentaries and research protocol papers; papers that predominately surveyed cancer patients under 18 years of age; papers that used an existing tool to evaluate cancer patient experience/satisfaction unless they provided additional useful advice; and papers that measured symptom burden only.

A systematic multiple method search strategy has been used in this review.¹³ **Table 1** provides a summary of the search strategy and search terms which were purposely broad to capture studies with cancer patients at all stages of disease and in different settings. The Scopus, PubMed, Medline, Embase, CINAHL, PsycINFO and Informit databases were systematically searched. Reference sections of textbooks and journal articles on cancer patient reported assessments, as well as major applicable journals (i.e. *Journal of Clinical Oncology*, *European Journal of Cancer*; *Cancer*; *BMC Cancer*; *Supportive Care in Cancer*) were hand-searched to check for additional relevant publications. Expert organisations currently working in field were also contacted for further evidence.

Keyword and secondary searches yielded 54 papers in total. Two reviewers independently assessed each study for eligibility for inclusion. The removal of duplicates and exclusion of

papers that were published prior to 2005; non-English papers where translations were unavailable; and studies set in developing countries left a total of 35 papers for inclusion. A further 9 papers were excluded as not investigating patient-reported measures. The full text was sought for 26 peer reviewed papers.

Twenty-six peer-reviewed research papers, which met the inclusion criteria and were of sufficient quality, were analysed. The assessed psychometric measurement properties of the cancer patient experience instruments in the studies were tabled (i.e. responsiveness, internal consistency, content validity, criterion validity, construct validity, interpretability, reproducibility and floor and ceiling effects)¹⁴ and are available in **Table 2**. A summary of included studies is available in **Table 3**. An assessment of quality of academic papers was undertaken using the Critical Appraisal Skills Programme.¹⁵ The Critical Appraisal Skills Programme (CASP) grew out of the work of the UK Critical Appraisal Skills Project in Oxford. The programme aims to support the appraisal of scientific evidence. Underpinned by a number of expert developed assessment checklists, CASP appraises the broad issues that need to be considered systematically when appraising research including considering if research is unbiased, results valid and an assessment of the importance of the results.¹⁶ Two reviewers independently assessed each study before collective agreement was determined.

Results

Study characteristics

The studies included in this review were primarily multi-method observational studies. Seven were conducted in The Netherlands^{2,17-22}, six in the United States of America²³⁻²⁸, four in the United Kingdom²⁹⁻³², two in each of France³³⁻³⁴ and Australia³⁵⁻³⁶ and one in each of Canada³⁷, Norway³⁸, Germany³⁹ and Greece⁴⁰. Only one of the studies was conducted across multiple countries⁴¹

Cancer patient experience was solely measured in six of the 26 studies.^{17,18,29,38,26,31} The remaining studies measured a combination of cancer patient experience and satisfaction except for one of the two Australian studies which measured needs related to the cancer patient experience of care.³⁵ Four of the included studies recruited cancer patients from treatment or diagnostic centres or clinics^{24,28,33,34}, two from a national insurance company database^{17,18} and one study recruited patients via a population based cancer registry.²³ The remaining studies recruited cancer patients from hospitals (inpatient and outpatients areas) or multiple settings including mailed surveys post hospital discharge or clinic visit. Study objectives differed across the included studies, with some utilising existing instruments as a base on which to add and test new items. Some investigators developed short form versions of existing instruments or attempted to validate psychometric properties of existing instruments, while others assessed validated tools under different conditions (e.g. cross cultural adaptation) or developed new cancer patient measures (and undertook some preliminary validation). Some undertook a combination of the objectives described above. The number of cancer patients participating in

each study ranged from 52 to 7,212. Almost 83% of the examined studies had over 100 participants. Response rates varied from 43% to 87%.

Target

A number of studies specifically targeted single cancer types i.e. five breast cancer specific^{17,18,19,20,34}, two targeting head and neck cancer^{21,30}, one targeting small cell lung cancer² and one targeting prostate cancer³¹. Four studies included selected multiple cancer types.^{23,26,28,33}

The remaining studies involved instruments measuring care experience among any adult cancer type. Instruments within the included studies assessed discrete medical treatments (such as chemotherapy) or service types (such as palliative care), while others focused on more general aspects of cancer care. One of the included studies investigated interpersonal or communication aspects of care interactions with healthcare providers,²¹ others also assessed experience and satisfaction with technical skills or clinical management²² while another assessed cancer care overall.¹⁵

Instrument development and structure

The majority of identified instruments across the included studies were originally designed for the oncology field. The newly developed instruments and those adapted from existing tools underwent a staged process of development which commonly included the generation of preliminary items, often using cancer patient interviews and/or focus groups, consultation with providers, and/or reviews of the literature, with some papers also reviewing specific evidenced

based cancer management guidelines. Pilot testing to support readability, interpretability/clarity and/or content validity was then frequently undertaken. Larger studies were then conducted to field test the final agreed item set and assess some or all of their psychometric properties. All but one of the instruments examined in the studies was based on a multidimensional framework with the number of items (i.e. patient questions) ranging from 15 to 152, within 1 to 15 different domains (i.e. categories).

Psychometric performance

The number of instruments assessing cancer patient experience that have sound psychometric properties across items was found to be low, a finding also reported in reviews of patient reported measures overall. The properties least tested were test-retest reliability, construct, convergent and discriminant validity, scale variability (floor/ceiling effects) and interpretability. The psychometric measurement properties tested in each instrument evaluated in this review can be found in **Table 2**. The European Organisation for Research and Treatment of Cancer (EORTC) IN-PATSAT32 survey¹⁷ which was designed to evaluate the cancer inpatient's perception of the quality of cancer care, and its organisation, is one of the strongest studies in terms of validity and reliability of a variety of items. So too is the REPERES-60¹⁸ survey which was designed to measure breast cancer patients' experience/ satisfaction of care. A number of the dimensions explored by the REPERES-60 survey are also found in the IN-PATSAT32 (exchange of information, information provision, interpersonal skills, availability, access, technical skills, comfort and global satisfaction).

Discussion

It is now generally recognised that there is a need for rigorous approaches to obtain patients' views on the care they receive. As a result, much effort has, and continues to be, committed to developing and evaluating survey measures that reflect healthcare experiences. Sound psychometric properties support an understanding of the 'if' and 'how well' an instrument measures cancer patient experience. Test-retest reliability was one property least tested in the studies examined. This potentially means that the measures examined may not provide similar results if administered at different times, even with the same cohort. The complexity of the cancer journey is often reflected in an unpredictable care routine, which emphasises the need for consistency in results of cancer patient experience measurements if improvement requirements are to be accurately identified and acted upon. Language and cultural issues have also been shown to affect test-retest reliability, making the direct implementation of instruments developed in other countries problematic.²⁹ Construct validity, which reflects the ability of the instruments to measure cancer patient experience, was also inadequately tested across the studies examined in this review. If instruments cannot provide confidence in their ability to measure cancer patient experience, they are much less likely to be applied in practice. A further gap in the testing of instruments was the responsiveness of the instruments to change and/or how well they capture variances in cancer care processes. The relational aspects of the different cancer patient experience measures are also largely unidentified (e.g. do some measures inform, augment or diminish others etc.). Poorly understood from existing studies is also the extent to which the measures may be able to capture differences in cancer care across care environments and time frames.

The value of using reliable measures to investigate cancer patient perceptions of their care experiences lies in the opportunity to understand the result of clinical procedures, practices and environment from the cancer patients' perspective, and generate information that can be used to improve care from this perspective. The interpretability of the results in relation to the potential effect on cancer patients was not explained in the included studies i.e. the relationship between results and the impact on the quality of the cancer care experience. This may be because there is no current agreed detailed definition of what the cancer patient experience means and which elements or stages are most important; therefore operationalising and measuring it with any real precision is currently very difficult. An ideal healthcare measure is said to have several key characteristics: (i) is based on agreed definitions; (ii) is specific and sensitive; (iii) is valid and reliable; (iv) discriminates well; (v) relates to clearly identifiable occurrences for the user; (vi) permits useful comparisons; and (vii) is evidence-based.³⁸ It may never be possible to establish the cancer patient journey that is best from the viewpoint of all patients or the true value placed on different aspects of cancer care by different patients at different times in the cancer journey.

This review examined a decade's worth of research on the development of instruments to measure the cancer patient experience of health care. Overall, it found that research in this area is still in the early stages of development and the extent to which the application of existing patient experience measures has led to improvements in patient centred care is unclear from existing literature on the topic. Moreover, when this area is compared to other complex healthcare measures, stark differences in progress are highlighted. For example, compared to patient experience measures, a much larger body of research has long been devoted to the development of psychometrically sound health-related quality of life (HRQOL) measures. In fact, by volume

of research publications, HRQOL studies surpass all other topics, for example, in the two years between 1988 and 1990 around 1400 articles were published.^{42,43} It is unclear at this stage whether patient experience measures will eventually attract similar interest among researchers and healthcare services alike, to further develop, validate and implement patient experience measures.

Limitations of the Review

The central limitation of this review of cancer patient experience measures is the potential non-inclusion of relevant articles and unpublished material. Our search strategy relied on key words assigned by authors and may have missed studies that are relevant to the review but were not identified. Another limitation is the assessment of psychometric properties which was based on individual study acknowledgement of testing, hence the quality of psychometric properties of instruments was not identified which may mean an overestimation of the psychometric performance of instruments or items therein. Finally, any cancer patient experience measures or items within existing quality of life instruments were not included in this review leading to a potential underestimation of available cancer patient experience measures.

Conclusion

Cancer patient experience measures are used, normally alongside other cancer patient reported measures, as indicators of quality cancer care. The currently available studies that inform the field of cancer patient experience measures are of different sample sizes, achieve different

precision across various psychometric properties of survey instruments, and have been tested for various purposes on different cohorts, in different settings and countries. While measures of cancer patient experience are not routinely collected in a systematic and consistent way, there are results from a number of research studies that include at least some validated or partially validated indicators of cancer patient experience that could be used to inform and drive further cancer patient experience indicator development.

Conflict

The authors declare that there is no conflict of interest

Acknowledgement

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Table 1. Search strategy summary

<p>Search Strategy</p>	<ul style="list-style-type: none"> • Papers published 2005-April 2015 (<2005 assessed for relevance and significance i.e. to complete a necessary picture). • Databases: Scopus, PubMed, Medline, Embase, CINAHL, PsycINFO and Informit • Manual searches of reference sections and citations of relevant textbooks and journal articles • Manual searches of major applicable journals • Consulted expert organisations working in field (Clinical Excellence Commission NSW and NSW Agency for Clinical Innovation) to identify articles and reports describing instruments, including subscales or items that assess dimensions of the cancer patient experience of health care.
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Key Words	<p>patient OR lay OR consumer OR user OR carer OR family OR care recipient AND cancer OR oncology OR malignancy AND experience OR satisfaction OR preference OR views OR perspectives OR opinions AND healthcare OR health service AND measure OR assess OR evaluate OR appraise</p>
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Table 2 Summary of the psychometric properties of all instruments measuring cancer patient experience¹

First Author	Content validity	Internal consistency	Construct validity	Reproducibility		Responsiveness
				Agreement	Reliability	
Arora 2011	0	+	?	?	?	?
Booij 2013	+	+	+	?	?	?
Boyes 2009	+	+	+	+	?	?
Brédart 2005	+	+	+	+	+	?
Brédart 2011	+	+	+	?	?	?
Damman	+	+	?	?	?	?

¹ Terwee C, Bet S, Boer M, van der Windt D, Knol D, Dekker J, Bouter L, de Vet H: Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol 2007, 60:34–42.

First Author	Content validity	Internal consistency	Construct validity	Reproducibility		Responsiveness
				Agreement	Reliability	
2009						
Defossez 2007	+	+	?	?	0	?
de Kok 2007	+	?	?	?	?	?
de Kok 2010	0	+	?	?	?	?
Fitch 2011	+	+	?	?	?	?
Harley 2009	+	+	?	?	?	?
Iversen 2012	+	+	+	+	+	?
Jean-Pierre 2011	+	+	+	?	0	?
Kleeberg 2005	+	+	?	?	?	?
Kritsotakis 2009	+	+	+	?	?	?
Llewellyn 2006	+	+	?	?	?	+
Lo 2009	+	+	?	?	?	?
Malin 2006	0	?	?	?	?	?
Ouwens 2007	+	?	?	?	+	?
Ouwens 2010	+	+	?	?	0	?
Tarrant 2009	+	+	?	?	+	?
Teno 2009	+	+	+	+	?	?
Trask 2008	+	+	?	?	+	?
van Weert 2009	+	+	0	?	?	?
Wright 2005	+	+	+	+	+	?
Young 2011	+	+	+	?	0	?

Table3: Summary of included studies

Main Author, Year, Aim	Method , Sample	In
<p>Arora et al. (2011)</p> <p>Aim: Develop and test a comprehensive survey to assess cancer survivors' perceptions of the quality of their follow-up care; identify the sociodemographic, clinical, and follow-up care related factors associated with survivors' quality-of-care assessments; and evaluate the</p>	<ul style="list-style-type: none"> • Cancer registry recruitment of leukaemia, bladder, and colorectal cancer survivors aged 20+ diagnosed 2 to 5 years previously. • All survey items underwent cognitive testing with 9 cancer survivors (with diversity in age, race, sex, and cancer type) to ensure items were understandable • Postal survey n = 623 (response rate 49.2%) 	<p>Assessment of Patient Care (APECC) survey largely from existing items added by investigators in new domains (Access-re specific items; Heal</p>
<p>Booij et al. (2013)</p> <p>Aim: Develop a quality cancer care questionnaire for the European Organisation for Research and Treatment of Cancer (EORTC) to measure cancer patients' experiences/satisfaction with hospital care.</p>	<ul style="list-style-type: none"> • Recruitment via national insurance company. • Expert group (healthcare professionals, patient organisations, health insurers and researchers) established and consulted for decisions on the creation and adaptation of the questionnaire. • Three focus group discussions held with 24 cancer patients to analyse the importance of questions. • Respondents over 18; had any type of cancer; last treatment <2 years prior to focus group/survey, (n=732- 50%) 	<p>Instrument (12 domains) derived from focus group findings and 12 items from EORTC questionnaire to assess patient satisfaction; the CQI questionnaire to assess patients' experiences with CQI hospital care to assess care quality and other factors. Netherlands patient experiences. Twelve domains: patient experience; aftercare; cooperation between healthcare professionals; patient choice; skills and knowledge of healthcare professionals</p>
<p>Boyes A. et al (2009)</p> <p>Aim: Develop and validate a short version of the Supportive Care Needs Survey (SCNS-LF59) to reduce respondent burden without compromising the psychometric</p>	<p>Secondary analyses of the data from two studies. The Supportive Care Review was conducted in 1995 and assessed the supportive care needs of 888 adult cancer patients using the SCNS-LF59. Unpublished baseline data collected from the first 250 participants in the Cancer Survival Study was used to test the convergent validity of the short-</p>	<p>New instrument (SCNS-LF59) within five domains: patient experience; system and information; patient care; living; patient care needs). New instrument psychometric properties. New instrument (content</p>

<p>Brédart et al. (2005)</p> <p>Aim: Study objective was to assess the psychometric properties of the European Organisation for Research and Treatment of Cancer (EORTC) IN-PATSAT32 when used in a large, international, cross-cultural context (The EORTC QLQ-SAT32 is designed to evaluate the cancer inpatient's</p>	<ul style="list-style-type: none"> • Patients diagnosed with cancer, aged 18+, hospitalised for at least three days, and be mentally fit to complete a questionnaire. • Patients N=647 from collaborating hospitals in nine countries completed the EORTC IN-PATSAT32 • Self-administered tool given to patients while in hospital to complete at home and post back within 6 weeks of discharge. A reminder letter 	<p>The EORTC QLQ- divided across three <i>the medical team;</i> (<i>organisation of care includes a questionnaire satisfaction.</i></p>
<p>Brédart et al. (2011)</p> <p>Aim: Validate a questionnaire (SAT-RAR) on patients' perception of care quality during radiotherapy for breast or lung cancer.</p>	<ul style="list-style-type: none"> • Questionnaire developed in several steps: (a) review of the literature (b) selection of items according to relevant themes identified in the literature and based on a cancer care satisfaction previously developed questionnaire (c) pilot testing of the preliminary questionnaire on 10 patients during radiotherapy in order to evaluate its relevance, content validity, comprehensibility, redundant items. • Patients with non-small cell lung cancer or breast 	<p>Psychometric analysis and consistently met of: <i>form and timing perception of the radio technicians; emotion of treatment; and g</i> (23 items). Scales and responses according</p>
<p>Damman et al. (2009)</p> <p>Aim: Develop an instrument - CQ-index Breast Care (CQI-BC) instrument to measure the care experience from the breast cancer patient perspective</p>	<ul style="list-style-type: none"> • Three focus group discussions to determine items for inclusion in pilot questionnaire, 27 patients (n = 11, n = 9 and n = 7). • Pilot oral questionnaire completed by 731 women (response 63%) filled in the experience survey. Selected from claims data of four health insurance companies. • Participants had various stages of diagnosis and disease progression; must have had breast care 	<p>The final instrument 118 items regarded domains: <i>Conduct of breast examination; practitioner Integration; Conduct of nurses; Autonomy regarding regarding follow-up professionals during</i></p>
<p>de Kok et al. (2007)</p> <p>Aim: Develop an instrument to assess quality of care in breast cancer patients.</p>	<ul style="list-style-type: none"> • Cancer patients' participants across a range of treatment modalities recruited from five hospitals. • Focus groups followed by concept mapping to determine relevant items for inclusion. 72 participants across eight focus groups. 67 participants across the six concept map meetings. Focus group participants had curative surgery in the previous 15 months; concept mapping participants had surgery in the previous 12 months. 	<p>6 key domains (55 <i>education; focus of care; respect for t admission</i></p>

<p>de Kok et al. (2010)</p> <p>Aim: Test a pilot instrument of assessment of professionals' performance and patients' needs in the care process from the perspective of</p>	<ul style="list-style-type: none"> • A pilot questionnaire was developed and sent by post to all breast cancer patients 17+ and mental competence as judged by the breast nurse and operated on in the previous 3 to 15 months in five participating hospitals (n=276 and response rate 	<p>Five key domains (<i>education regarding postoperative treatment; breast nurse, service education regarding</i></p>
<p>Defossez et al. (2007)</p> <p>Aim: Adapt existing Consumer Satisfaction Survey (validated in French)</p>	<ul style="list-style-type: none"> • Literature review and two focus groups with 30 breast cancer patients used to generate items and identify domains. • Test questionnaire trialled with breast cancer patients to assess understanding and comprehensiveness of items. • Postal survey of 850 (87% response) patients from two regions to validate new questionnaire. Sent one month after end of 	<p>Developed additional focus groups and expert breast cancer patients items, 13 domains: <i>Access to secondary communication skills; Competence of secondary doctors; Choice am</i></p>
<p>Fitch, M. and McAndrew, A. (2011)</p> <p>Aim: Develop a measure to gather patient feedback regarding information given to them in healthcare visits.</p>	<ul style="list-style-type: none"> • The issues cancer patients previously reported of importance to them selected as domains for the new instrument • Tested for clarity in 10 patients attending an outpatient appointment. • Convenience sample of 540 cancer patients with a large range of cancers and in various stages of 	<p>Two key domains (<i>importance; Inform</i></p>
<p>Harley et al. (2009)</p> <p>Aim: Adapt the Components of Primary Care Index (CPCI) to be applicable to oncology outpatients and assess the reliability and validity of the adapted instrument (renamed the Medical Care Questionnaire [MCQ]).</p>	<ul style="list-style-type: none"> • Instrument development in phases (1) reviewed the literature and examined existing measures (2) Selected instrument (CPCI) reviewed by an expert panel using a stepwise consensus procedure (3) Adapted 21-item MCQ administered to 200 outpatients attending oncology appointments - instrument refined (4) 21-item MCQ completed by 477 oncology outpatients (<i>in hospital and by post</i>) who could 	<p>Three domains (1) "Communication" "Coordination" of physicians' accumulation patient; and "Pref</p>
<p>Iversen, H. et al (2012)</p> <p>Aim: Describe the development and psychometric evaluation of the Cancer Patient Experiences Questionnaire (CPEQ) in Norway.</p>	<ul style="list-style-type: none"> • Instrument development in phases (1) literature review of existing questionnaires (2) patient interviews (3) expert-group consultations (4) pretesting questionnaire (5) national survey. • Questionnaire tested in interview with 12 patients • Postal survey of 7,212 cancer patients attending 54 hospitals in all 4 health regions. • Adult cancer patients who attended an outpatient clinic or been discharged from an inpatient ward. 	<p>The final questionnaire outpatient experience; <i>contact; doctor care organisation; patient next of kin. Seven experiences: as ab The questionnaire hospital care not c outpatient or inpat</i></p>

<p>Malin et al. (2006)</p> <p>Aim: Assess newly diagnosed lung and colorectal cancer patients on their personal characteristics, decision making, experience of care, and outcomes using the baseline CanCORS patient survey.</p>	<ul style="list-style-type: none"> • Survey developed from expert opinion and adaptation of previously validated tools. Questions about patients' experiences of their care were adapted from several existing surveys, including Consumer Assessment of Health Plans Study (CAHPS) adult core survey, a survey of cancer patients developed by the Picker Institute, the Northern California Colorectal Cancer Study Patient Survey, and the NCI's Assessment of Patients' Experience of Cancer Care (APECC) • Survey was designed to capture information about the initial treatment decision-making process - administered approximately 4 months post-diagnosis. 	<p>Twelve (12) Dom experience items: care: coordination provided, access to discrimination</p>
<p>Ouwens et al. (2007)</p> <p>Aim: Development of measures to assess the process of care for patients with head and neck cancer</p>	<ul style="list-style-type: none"> • Development of measures based on integrated care literature, national evidence-based guidelines for patients with head and neck cancer, and the opinions of professionals and patients • 15 professionals and 30 patients individually interviewed. • Indicators tested via postal survey on a population of 180 newly referred patients (newly 	<p>The set of 23 exper divided into 3 dom <i>patient-oriented q organizational qu medical/technical</i></p>
<p>Ouwens et al. (2010)</p> <p>Aim - Develop indicators of patient-centred cancer care and tested on a population of patients with Non-Small Cell Lung Cancer (NSCLC).</p>	<ul style="list-style-type: none"> • Recommendations for patient-centred care extracted from clinical guidelines, and patients and consumers interviewed (n=30 head and neck cancer and n=7 patient representatives). Recommendations translated into measures and developed into a questionnaire. • Patients newly diagnosed non-small cell lung cancer treated in six hospitals in the Netherlands 	<p>56 items across 8 <i>Up, Communicati Family Involvement Coordination, Phy and psychological</i></p>
<p>Tarrant et al. (2009)</p> <p>Aim: Formally evaluate the Prostate Care Questionnaire (PCP-Q) reliability, validity and acceptability to patients and service providers (<i>The PCP-Q is a measure developed from research designed to determine the issues most important to prostate cancer patients, including a literature review of the experiences of patients of prostate</i></p>	<ul style="list-style-type: none"> • Each of 5 hospitals drew a consecutive sample of all patients diagnosed with, or treated for, prostate cancer within the past two years & at different stages of care. Postal questionnaires were returned by 865 patients (69.2%); 355 completed Sections A, B, C and F (response rate: 61%), and 510 completed Sections D, E and F (response rate: 77.7%). • To assess criterion validity, 935 patients were also sent sections of the National Centre for Social Research Shortened Questionnaire; to 	<p>PCP-Q questionna sections- <i>Section Explanation Expe the problem serio hospital; Explana care; Appointmen treatment decisio Making treatment diagnosis; Length Treatment and dis discharge: Treatm</i></p>

<p>Teno JM, et al. (2009)</p> <p>Aim: Validation of new measures of the quality of care at the time of diagnosis and treatment for life-limiting advanced cancer.</p>	<ul style="list-style-type: none"> • Measures developed via focus groups, review of guidelines, and an expert panel were used to construct two surveys of the quality of cancer care. • First survey administered shortly after diagnosis with or progressed to an advanced stage of cancer (n=206). Second survey administered 1 to 2 months later post completion of at least one treatment cycle. Of the 206 time 1 respondents, 	<p>Three domains (4... <i>the time of diagnosis</i> <i>time of treatment</i> <i>patient experience</i> <i>items: How often</i> <i>providers allow you</i> <i>many questions as</i> <i>treatment plan? H</i> <i>that your oncolog</i></p>
<p>Trask et al. (2008)</p> <p>Aim: Psychometric testing of the Cancer Therapy Satisfaction Questionnaire (CTSQ)</p>	<ul style="list-style-type: none"> • Cancer Therapy Satisfaction Questionnaire (CTSQ) was originally developed after interviews and focus groups with patients • A total of 361 participants (18 years or+, English literate, available for follow-up evaluation, and receiving treatment). Study participants randomly assigned to complete either the baseline assessment only or both the baseline and follow-up assessments. A subsample of 88 participants completed follow-up questionnaires 1 week after 	<p>Final version of th... domains: <i>Expecta</i> <i>about Side Effects</i> <i>Therapy.</i></p>
<p>van Weert et al. (2009)</p> <p>Aim: Develop and assess psychometric properties of a patient-centred instrument - QUOTE^{chemo} (QUOTE - Quality Of care Through the patients' Eyes) to measure needs and experiences with communication preceding chemotherapy treatment</p>	<ul style="list-style-type: none"> • Items developed via existing measure, literature review and five focus group interviews (n = 33) as well as one-to-one interviews with cancer patients (n = 5). • Eligible patients to test the instrument identified through the hospital records of 10 hospitals in the Netherlands. The QUOTEchemo questionnaire was sent to patients of each hospital that had 	<p>Seven key domain... related informatio... Rehabilitation info... information, Inter... Tailored commun... communication</p>
<p>Wright EP. et al (2005)</p> <p>Aim: Develop and preliminarily evaluate a Social Difficulties Inventory (SDI) for use in oncology practice.</p>	<ul style="list-style-type: none"> • Items developed via (a) existing measures, (b) literature review, (c) 18 patient focus groups and 12 patient interviews involving 96 purposively selected patients and (d) staff (49 health/social welfare oncology professionals - 7 focus groups). • Expert review panel to assess content validity. • Questions constructed and pre-tested (n = 42) • Psychometric evaluation (n = 271) to assess frequency of endorsement, factor structure 	<p>Twenty one items... Physical ability, P... Contact with other... include: Have you... maintaining your... had any difficulty... domestic chores?... cooking, shopping... difficulty with ma...</p>

<p>Young et al. (2011)</p> <p>Aim: Develop a questionnaire to measure patient experience of cancer care coordination</p>	<ul style="list-style-type: none"> • Questionnaire items developed on the basis of literature review, focus groups and interviews with cancer patients, carers and clinicians. • 686 English speaking patients recently treated for newly diagnosed cancer, from 28 centres in New South Wales completed the self-administered questionnaire • Sample 1: patients (n= 245) recruited who had been treated between three and 12 months previously (considered optimal timing as patients assumed to have experienced full range of care 	<p>Final instrument h</p> <p>‘Communication’</p> <p>items including: <i>o</i></p> <p><i>access to and navig</i></p> <p><i>healthcare system</i></p> <p><i>contact” person, n</i></p> <p><i>understanding of i</i></p> <p><i>effective communi</i></p> <p><i>amongst the multi</i></p> <p><i>health service pro</i></p> <p><i>in a complementa</i></p>
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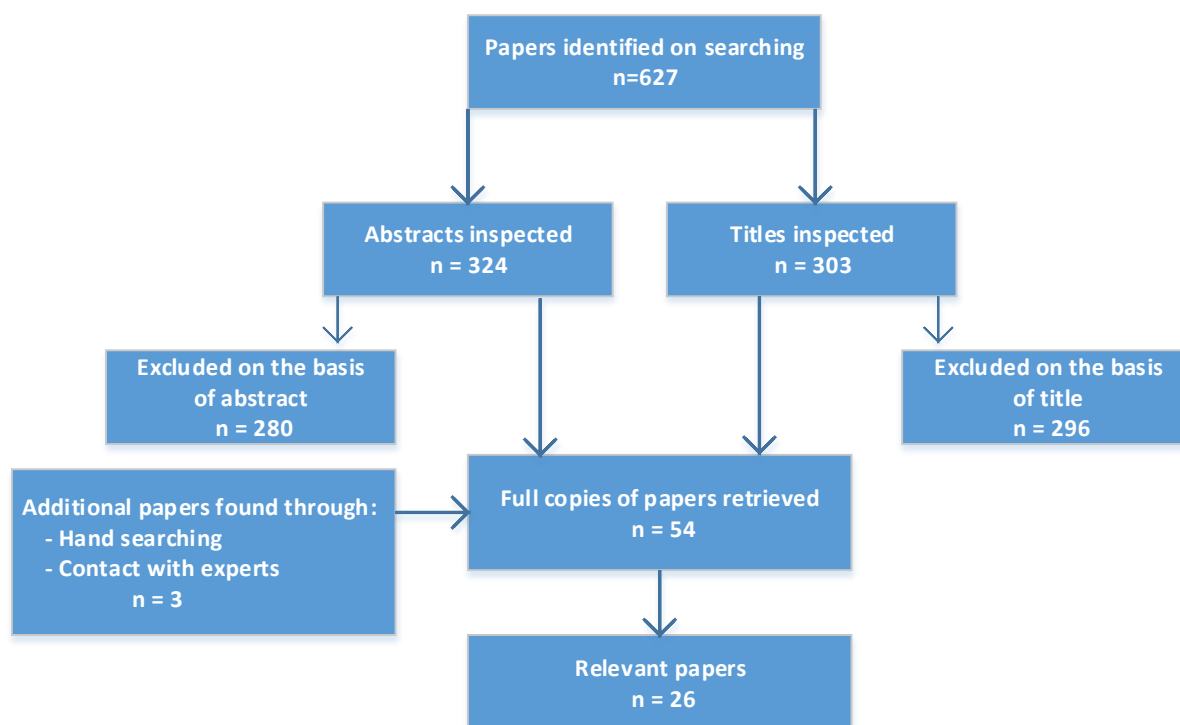


Fig. 1 Flow chart summarising number of studies identified and ultimately included