

How should we measure emesis in palliative care?

Carina Saxby, Rajeena Ackroyd, Sarah Callin and Catriona Mayland Palliative Medicine, Yorkshire Deanery, Leeds and **Suzanne Kite** Palliative Medicine, Leeds General Infirmary, Leeds

There are many assessment tools available to measure emesis. This Association for Palliative Medicine Science Committee Task Group undertook a review of the validity and suitability of the assessment tools available to measure nausea, vomiting and retching within a palliative care population. Electronic databases were searched from 1970 to 2004. Both specific and global tools were identified and reviewed for their validity, reliability and suitability for our patient population where coexisting cognitive impairment and significant co-morbidities may make accurate assessment of symptoms difficult. Within specific palliative care scenarios namely daily clinical assessment, prevalence surveys and randomized controlled trial settings, the team reached a consensus on which tools had the greatest evidence to recommend them, either for immediate use or for further validation studies. An ideal measurement tool for the assessment of nausea, vomiting and retching has not yet been developed. *Palliative Medicine* 2007; **21**: 369–383

Key words: assessment measures; cancer; nausea; palliative care; retching; vomiting

Introduction

‘There may be as many scales for assessing nausea and vomiting as there are investigative groups studying the phenomenon.’¹

Nausea, vomiting and retching are all prevalent in palliative care patients^{2–4} and the cause of much suffering. Whilst related to each other, and to other symptoms such as reduced appetite and cachexia, nausea, vomiting and retching are all separate entities. For symptoms, which are so prevalent, there is a marked lack of consensus regarding assessment tools for clinical monitoring and research purposes. There are several reviews of the assessment of nausea and vomiting in oncological practice,⁵ but few in palliative care.⁶

Although vomiting is an observable and measurable phenomenon in terms of frequency, consistency and volume, nausea is subjective and, hence, reliant on patient reports. Nausea has dimensions of frequency, intensity and duration as well as quantitative and qualitative aspects.⁵ Within the literature, retching is rarely measured independently. However, direct comparisons between different studies can only be made if a clear indication is given of whether or not retching comprises an emetic episode.⁷ Throughout this paper, we have chosen to use the term emesis to describe all three parts of the symptom complex.

The aim of this paper is to identify the tools available to measure nausea, vomiting and retching within a palliative care population. We also aimed to assess the suitability of such tools for everyday clinical use, for prevalence studies and for research trials comparing anti-emetic interventions. We were interested in both specific tools measuring nausea, vomiting and retching, and global symptom assessments that include the measurement of these symptoms. In addition to evidence of the validity and reliability of the tools, we were interested in speed and ease of their administration. Indirect measurement of nausea, such as physiological correlates and humoral markers⁵ and the measurement of related symptoms, were outside the scope of this study.

This paper was undertaken on behalf of the Science Committee of the Association for Palliative Medicine.

Method

We searched electronic databases Medline, Cinahl, Embase and British Nursing Index as well as the Cochrane Library and Cancer Literature from 1970 to 2004. Medical Subject Heading (MeSH) searches and simple word searches (using wildcards where appropriate) were carried out on the four main elements in the search:

- 1) Nausea/vomiting/retching.
- 2) Cancer/palliative care.
- 3) Scales and assessment measures.
- 4) Validation measures.

The initial search was limited to studies in humans published and validated in English. A librarian experienced in

Address for correspondence: Dr S Callin, SpR in Palliative Medicine, Yorkshire Deanery, Leeds Pain Management Service, L Ward, Seacroft Hospital, York Road, Leeds LS14 6UH, UK.
E-mail: sarahcallin@gmail.com

systematic reviews conducted an independent search using the same criteria and the two search results were compared and combined.

After a review of the abstracts, 35 tools were selected to be evaluated further. We excluded trials purely comparing chemotherapeutic agents and focused on the validation of new and existing tools in the palliative care/oncology setting.

Using a standard data extraction tool, developed for this paper, two members of the team independently assessed each paper for the quality of evidence to recommend the tool in terms of reliability and validity, and the relevance of that tool to our patient population. People receiving palliative care often have poor performance status, a rapidly changing clinical picture, and multiple co-morbidities including cognitive impairment. Suitability of the available tools was considered in light of these factors. The following factors were considered important when evaluating each tool: that the tool was easy to understand, that it had a short completion time and that it was straightforward to score.

The tools were subdivided into those contained within global assessment tools and those specifically designed to evaluate nausea and vomiting in our chosen population. From the 35 tools identified from their abstracts, eight were excluded at this stage as they did not meet the inclusion criteria.

As the appropriateness of each tool may vary depending on the context in which it is being used, the team reached a consensus about which assessment tools would be most appropriate for a particular context. This was based on the degree of evidence for each tool and their applicability to the palliative care population. The contexts considered in the use of tools were:

- 1) Daily clinical assessment.
- 2) Prevalence studies.
- 3) Randomized controlled trial settings.

Results

Brief descriptions of the different tools are presented in Table A1 (Specific tools) and Table A2 (Global tools). The tables (Appendix 1 and 2) also contain an overview of the psychometric properties of each tool as well as their potential advantages, disadvantages and uses in a palliative care population. Table 1 contains the summary of the tools recommended for use in the assessment of emesis for each chosen context. Reasons for exclusion of tools identified in the literature review are listed in Table A3 (Appendix 3).

Discussion

Nausea, vomiting and retching are common and distressing symptoms. The evidence base to support various anti-emetic

Table 1 Summary of recommendations for tools to measure emesis in palliative care

Purpose	Specific tools	Global tools
Prevalence studies	VCS	EORTC QLQ-C30 PACA ASDS-2 ^a
Daily clinical assessment	VAS NRS INV-R ^a FLIE	MQLS PACA ASDS-2 ^a
Research	VAS NRS INV-R ^a	EORTC QLQ-C30 ESAS RSCL-M

^aRequires validation in a palliative care population.

ASDS-2, Adapted Symptom Distress Score; EORTC QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30; ESAS, Edmonton Symptom Assessment Scale; FLIE, Functional Living Index-Emesis; INV-R, index of nausea, vomiting and retching; MQLS, McMaster Quality of Life Scale; NRS, numerical rating scales; PACA, Palliative Care Assessment tool; RSCL-M, Modified Rotterdam symptom checklist; VAS, visual analogue scales; VCS verbal categorical scales.

interventions in palliative care is largely lacking. This may be because good clinical outcomes have been achieved empirically or because clinical trials in this population have proved difficult to design and complete. There has certainly been a lack of clarity in some published work regarding the distinction between nausea, vomiting and retching. Patients may also struggle with the terms: in an American study, two-thirds of medical, surgical and gynaecology patients did not understand the term 'nausea'.⁸

However, there are a large number of tools available to measure nausea, vomiting and retching (Tables A1 and A2). Different tools are more suited to assessment in different situations, and direct comparison of tools is most relevant within the specific purpose and setting in mind. We chose daily clinical assessment, prevalence surveys and research studies comparing anti-emetic interventions, as the scenarios within which to compare tools. Some general observations will be made about the tools available, and then the use of assessment tools for nausea, vomiting and retching in each of these three palliative care scenarios will be considered.

Self-report versus observer-report tools

There is debate about the benefits and burdens of palliative care patients completing self-report questionnaires. Vomiting and retching can be measured objectively but nausea is a subjective sensation, which only the patient can accurately define. Some see self-reporting as essential for a valid and reliable basis for the study of effective interventions for nausea, vomiting and retching.⁶ Others observe that

self-reporting is useful but that anti-emetic interventions can cause sedation, mood alteration, disorientation or memory loss, reducing possible advantages of self-reporting.⁷ As a patient's condition deteriorates, the use of an observer administered tool may be more appropriate.

Behavioural scales have also been developed.⁹ In the pain literature, there is doubt whether behavioural phenomena can be relied upon to measure pain accurately¹⁰ and this may also be true for other subjective sensations such as nausea. Within palliative care, other observer-report tools are more likely to be used for patients who cannot self-report.

Specific assessment tools

Tools that are specifically designed for the assessment of emesis include unidimensional scales, measuring one specific aspect of the symptom and multidimensional scales that combine different methods to provide a more comprehensive assessment of emesis. Although many of the specific tools identified have been validated in chemotherapy out-patients, none have been extensively validated for the assessment of emesis in the palliative care population.

Four types of unidimensional emesis scales are described: visual analogue scales (VAS), analogue continuous chromatic scales, numerical rating scales (NRS) and verbal categorical scales (VCS), which include Likert scales. The latter is a bipolar scaling method asking respondents to specify their level of agreement to a particular statement. It is traditionally a five-point scale usually ranging from 'strongly disagree' to 'strongly agree'.

The relative merits of analogue versus discrete scales have long been debated in the pain literature. Studies simultaneously assessing nausea in chemotherapy patients using both VAS and VCS found no major differences between them.^{11,12} Some people find that VAS is difficult to use, in particular, converting a subjective sensation to a straight line.¹⁰ In a study of comparing three unidimensional scales in a chronic pain population, Kremer *et al.*, concluded that a categorical or numerical rating scale should be used in preference to VAS, as 11% of patients were unable to complete VAS compared to 2% with a numerical rating scale.¹³ The mean age of patients failing to complete the VAS was significantly greater than those who completed it successfully. The author recommended that in patients whose abstracting abilities and/or compliance are low, NRS should be used to measure pain intensity.¹³

There is no consensus on the optimum number of points for a unidimensional assessment scale for emesis.¹² It is important, however, to use the same rating scale for the same patient over time. Maguire and Selby¹⁴ and Borjeson *et al.*,¹² highlight the difficulties in interpreting results from visual analogue scales. Attempting to convert those values into verbal categories is fraught, as while one person may rate a value as representing the equivalent of 'severe' on a VCS, another may rate the same value as only 'moderate'.

Maintaining the same rating scale helps to reduce this problem and is essential for statistical analysis. The statistical calculations for a continuous variable (VAS) will differ to those used for a discrete scale and this may influence the choice of tool.

Global symptom assessment tools

It was not the purpose of this paper to compare the global tools in any way other than their ability to identify, quantify and qualify nausea and vomiting in a palliative care population. Articles considering what makes an effective quality of life (QOL) tool are available.¹⁴⁻¹⁷

Global tools have the potential to capture a more complete picture of the emetic symptom experience than do specific tools. However, most global symptom assessment tools have been developed to measure critical outcomes of treatment or care in response to various oncological interventions or models of palliative care. Few tools are suited for screening in clinical assessment. None have been developed specifically to evaluate the global symptom experience of emesis.

There are a number of global symptom assessment tools which have been developed and validated in a palliative care population: Edmonton Symptom Assessment Scale (ESAS),¹⁸ revised Hospice Quality of Life Index,¹⁹ Suffering in Terminal Illness (STIL),²⁰ Palliative Care Assessment tool (PACA),²¹ Resident Assessment Instrument in Palliative Care²² and McMaster Quality of Life Scale.²³

Others, such as Symptom Experience Scale,²⁴ Quality of Life Index (QLI),²⁵ Memorial Symptom Assessment Scale (MSAS)²⁶ and Adapted Symptom Distress Scale-2²⁷ have not been tested in the palliative care setting but have relevant qualities. The Adapted Symptom Distress Score (ASDS-2) has a short completion time as well as good psychometric properties. Of the tools reviewed, only the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30)²⁸, ASDS-2, STIL, Modified Rotterdam,²⁹ Revised Rotterdam,³⁰ PACA and QLI look at nausea and vomiting as separate entities. The ESAS has the flexibility of adding vomiting as an extra item. None of the tools specifically assess retching.

A group of tools including The McGill Quality of Life Questionnaire, Palliative Care Outcome Scale³¹ and the Patient Evaluated Problem Score³² require the patient to identify the symptoms that most trouble them. These tools, while affording patients the opportunity to express if emesis is a problem, were not felt to be specific enough to consider for the purposes of this review.

Prevalence studies

Prevalence studies require assessment of symptoms in large populations. The ideal tool must therefore be simple and quick to complete with minimal instruction required. The

ability to use mailed or telephone questionnaires may also be advantageous. As the main aim will be the recording of the presence or absence of nausea, vomiting and retching individual unidimensional scales are likely to provide adequate data. We suggest that in palliative care the VCS would be the most appropriate tool to use in a prevalence study for the reasons given above. The VCS also has the advantage of having the highest patient preference for the unidimensional scales in the chronic pain study by Kremer *et al.*¹³

Most global tools take longer to complete than specific tools, so may be less suited for prevalence studies. If a global tool is to be used, nausea, vomiting and retching should be enquired separately. Of the global tools that look at both nausea and vomiting, the EORTC QLQ-C30 and the PACA, have been validated in palliative care patients and do not burden the patient greatly. The former is a self-report questionnaire reported to take oncology patients less than 12 minutes to complete²⁸ but in a palliative care population it took up to 18.5 minutes to complete the questionnaire unaided.³³ The PACA is concise and easy to use. It is completed by a healthcare professional who asks specific questions about the patient and has been validated in the hospital setting. There are anecdotal reports of the use of PACA in other care settings but formal validation of use in these areas has not been undertaken. Although not validated in a palliative care population the ASDS-2 is also a short 5 minutes self-report detailing the prevalence of nausea and vomiting. It merits validation in palliative care.

Research

Trials comparing anti-emetics or studies monitoring the impact of interventions may require different assessments of emesis. Given the nature of palliative care research, key considerations in choosing a tool will be pre-trial statistical power calculations, the sensitivity of the assessment tool to detect changes over time and the resources available to the investigator(s).

Unidimensional scales

Within the pain literature simultaneous use of scales has led to several authors recommending the use of VAS in preference to VCS primarily because they are considered to be more sensitive.³⁴ Borjeson investigated the concordance between VCS and VAS in assessing nausea in chemotherapy patients and showed the ratings on the VCS and VAS were well related.¹² For some patients changes in the level of nausea were noted earlier on the VAS. When following patients over time a VAS may therefore be more sensitive to change and justify the need for increased instruction.¹² NRS may

provide an alternative to the VAS for older or frailer patients, or for those with mild cognitive impairment.^{13,34}

Multidimensional tools

A more comprehensive assessment of emesis may be required, for example, in a trial to investigate a new anti-emetic. Multidimensional tools such as the revised Rhodes index of nausea, vomiting and retching (INV-R)³⁵ provide data on the frequency, the amount, the duration and the distress caused by each of the symptoms. The revised form is relatively simple and easy to use and comprises eight five-point Likert type scales with check box inserts. It has been used in trials of anti-emetics in chemotherapy-induced nausea and vomiting³⁵ but to date has only been used for short-term follow-up (72 hours). Validity for longer term follow-up and sensitivity to change needs to be determined and we would recommend that it be validated in a palliative care population.

With regards to global tools, the ESAS, Revised Rotterdam Symptom Checklist (RSCL) and the EORTC QLQ-C30 have been used in palliative care patient populations^{33,36,37} and clinical trials. The latter includes nausea and vomiting and is simple to use.^{28, 33} As noted above, in palliative care patients it took longer and required more help to complete.³³ The mode of completion, ie, self-completion versus interview, did not appear to influence the distribution of the scores and a palliative care module is being developed.

The ESAS is brief and easy to use, it is established in clinical practice and consists of nine 10 cm VAS relating to specific symptoms, including nausea. Vomiting can be inserted as an optional 10th symptom. It is designed for longitudinal assessment over time and is completed by the patient alone, the patient with help or by a caregiver alone. In a study of oncology patients¹⁸, which compared the ESAS, Functional Assessment of Cancer Therapy-general questionnaire³⁸ and MSAS, all tools could be completed in 5 minutes, however, more explanation was required for the ESAS than for the other two. Difficulty in understanding the ESAS was more pronounced in elderly and severely ill patients, who are more likely to predominate in a palliative care setting. Rees and Hardy³⁶ did not find ESAS a practical tool in patients with poor performance status, which was at variance with the results of Bruera *et al.*³⁹

The RSCL and the Modified Rotterdam symptom checklist (RSCL-M) both include nausea and vomiting. The RSCL-M was devised and validated in cancer patients in the US and differs from the RSCL in its increased emphasis on physical symptoms. The questions relating to the psychological dimensions of QOL have been omitted. The RSCL has been used in palliative care patients. In a hospice population, only 53% of patients were well enough to fill it in on admission and there was a high attrition rate.³⁷

Clinical assessment

Clinical assessment of emesis requires an initial assessment to identify the presence of emesis and associated symptoms, and may form part of a wider global QOL evaluation. Regular reassessments may be informal, or formal using qualitative or quantitative tools. Qualitative methods using patient journals, logs and diaries have been described.⁶ However, our focus here is on quantitative methods.

Where formal tools are used, important practical factors include ease of use and time to complete any questionnaire/measurement. Unidimensional tools can be used and in this situation, as in research settings, a VAS may be more sensitive to changes than a VCS allowing for earlier recognition of changes in individual patients and appropriate instigation of treatment. VAS is especially useful when repeated tests over time are required.^{14,16,17} The improved completion rates and verbal administration of the NRS give some advantages and may allow for easier collection of data in a population where cognitive impairment is common. Its use in the assessment of pain has been validated in palliative care and it has demonstrated sensitivity to treatment effect.^{40,41}

If a more comprehensive assessment is required, then the INV-R may again be helpful. The impact of symptoms on function is also likely to be relevant for clinical assessment and use of the Functional Living Index-Emesis (FLIE)⁴² may add valuable information. The latter has only been used in chemotherapy-induced nausea and vomiting and the validity for repeated long-term follow-up and sensitivity to change for both the INV-R and FLIE has not been determined.

From the global tools, the ASDS-2 is a revised version of The Symptom Distress Scale developed by McCorkle and Young.⁴³ A 31 item, five-point Likert type self-report instrument was developed by Rhodes and Watson that provides a total symptom experience score, symptom occurrence score, symptom distress score and subscale scores. Although it has not been validated in a palliative care population we feel that the ASDS-2 has sufficient qualities to recommend its validation in this population. The ESAS is used in daily clinical assessment and its merits and limitations have been discussed earlier.

The McMaster QOL assessment tool has been specifically designed for palliative care patients and is described as taking 3 minutes for carers and health professionals to complete, although for patients this figure varied between 3 and 30 minutes.²³ It is sensitive to changes in the patients' condition and allows physical and non physical aspects of QOL to be monitored separately.

For ease of use and established validity in a palliative care population we would recommend either the McMaster or PACA. The PACA is completed by the health care professional, which may be advantageous in patients with a deteriorating clinical picture. It has a very good reliability for vomiting but only moderate for nausea.

Conclusion

Our summary of recommendations for tools to assess nausea, vomiting and retching in a palliative care population are summarized in Table 1. Our suggestions are based on the evidence available within specialist palliative care, which is limited. Further validation studies would inform the choice of tools available to clinicians and researchers and develop the understanding, assessment and treatment of these common and distressing symptoms.

In palliative care, the high incidence of cognitive impairment, fatigue and significant co-morbidities require us to choose tools where ease of completion is a priority. Unidimensional tools are the most convenient and sensitive tools currently available. If information regarding distress or effect on functioning is important then multidimensional tools should provide adequate specific data relating to the impact of emesis on the patient. Scales that assess symptom severity, distress and frequency are preferable. Global QOL tools encompass the impact of not only emesis but many other physical, psychological and spiritual issues on the patient and they may be helpful in building a global picture of a patient's condition that are unlikely to be specific enough to glean sufficiently sensitive information about the direct impact of emesis alone on the patient. They may be more burdensome for patients to complete and this is particularly relevant when regular repeated assessments are necessary.

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Appendix 1

Table A1 Specific tools that may be considered in the assessment of emesis in a palliative care population

Instrument	Description	Evidence	Use in palliative care for assessment of emesis	Pros	Cons
Visual analogue scale (VAS)	One hundred millimetre long vertical or horizontal line with anchors at each end measuring 0 (no symptom at all) and 100 (very high symptom intensity)	Validated for the assessment of symptoms including pain in cancer patients, ⁴⁰ and chemotherapy induced nausea and vomiting (CINV) ^{11,44} Good agreement with ACCS and VCS for assessment of CINV Acceptable reliability test-retest (0.83) ⁴⁵	Intervention studies: Bruera <i>et al.</i> ^{46,47} Descriptive/prevalence studies: Fainsinger <i>et al.</i> ⁴	Identifies change in symptoms earlier than VCS ^{11,12} Statistical problems with use of multiple VAS ³⁸ but has been shown to be valid and reliable – see Edmonton Symptom Assessment scale Repeated measurements feasible ⁴⁸ Fewer language issues	Only measures quantitative aspect of one symptom Requires careful explanation and validity depends on instructions ⁴⁹ Some patients not able to convert subjective experience to measurement on line ¹⁰
Analogue continuous chromatic scale (ACCS)	Coloured horizontal strip, 100 mm long and 25 mm wide, containing no markings except for an anchor point at each end – colour is graduated from left to right	Validated for an assessment of chemotherapy induced nausea ¹¹ Good agreement with VAS and VCS for assessment of CINV (chemotherapy induced nausea and vomiting)	No studies identified	No major difference when compared with VAS in assessment of CINV but found to be slightly less sensitive ¹¹	Limited psychometric testing
Verbal categorical scale (VCS) (including Likert Scales)	Discrete scale with 3 or more points with various verbal ratings (eg, Overall nausea index, Lewis nausea and vomiting scale ⁵⁰ , Common toxicity criteria ⁵¹)	Validated for the assessment of symptoms including pain in cancer patients ⁴⁰ and CINV ^{11,44} Good agreement with ACCS and VAS for assessment of CINV Good test-retest reliability ($r = 0.90$) but only with small number of patients ($n = 20$) ⁵⁰	Intervention studies: Corli <i>et al.</i> ⁵² Bruera <i>et al.</i> ⁵³ Descriptive/prevalence studies: Vainio <i>et al.</i> ⁵⁴ Donnelly <i>et al.</i> ³	Easier to use than VAS especially in older people (Kremer <i>et al.</i> ¹³)	Less sensitive than VAS when following patients over time ¹² May be language issues Mixing variables can be confusing eg, function and nausea
Numerical rating scale (NRS)	Discrete scale with three or more points with numerical ratings, anchored at each end with verbal measures of symptom component	Validity established in assessment of pain in cancer patients ⁴⁰	Intervention studies: Eisenchlas <i>et al.</i> ⁵⁵	In assessment of pain found to be more user friendly than VAS with better compliance (Jensen ⁴¹ , Kremer <i>et al.</i> ¹³) Recent study found hospice patients were able to complete 11 point NRS for assessment of pain ⁵⁶	Only measures quantitative aspect of one symptom

Appendix 1 (Continueud)

Table A1 (Continued)

Instrument	Description Visual analogue scale (VAS)	Evidence	Use in palliative care for assessment of emesis	Pros	Cons
Index of nausea, vomiting and retching-revised (INV-R) ³⁵	Eight-item five-point Likert type scale with check box word inserts Patient completes the INV every 12 hours for 72 hours eg, post-chemotherapy	Validated for assessment of nausea, vomiting and retch in different populations including oncology, obstetric, medical and surgical patients Concurrent validity established ($r = 0.83$ – 0.87) Good construct validity Good internal consistency reliability (Cronbach's $\alpha = 0.89$ – 0.97 , split-half procedure 0.83 – 0.99)	No studies identified	Comprehensive nausea, vomiting and retch and assessment including frequency, amount, duration and distress More user-friendly than previous versions Large print Twelve hour time frame	
Nausea questionnaire (NQ)	Consists of VCS measuring distress of nausea, VAS measuring severity of nausea and a descriptor list	Individual components validated in CINV and anticipatory nausea ⁴⁴	No studies identified	Measures distress and severity of nausea	
Functional Living Index-Emesis FLIE ⁴²	18-item, seven point 100 mm VAS FLIE has 3 day recall	Validated for the assessment of the impact of chemotherapy induced nausea on daily function (Lindley <i>et al.</i> ⁴²)	No studies identified	Most questions related to impact of nausea/vomiting on patients daily function – may be a strength depending on type of study and outcome measure chosen	May be difficult to distinguish loss of function due to other causes
Modified FLIE ⁵⁷	Modified FLIE has 5 day recall	Mod FLIE Good internal consistency (Cronbach's $\alpha = 0.79$) Acceptable construct and convergent validity (Item-domain correlations stronger within ($r = 0.74$ – 0.97) than across domains ($r = 0.52$ – 0.76))		5 day recall	
Behaviour scales eg, Chapko <i>et al.</i> ⁹	Consists of a list of behaviours associated with nausea. These are watched for and then recorded by an observer over a period of time	Validated in assessment of nausea in patients receiving high dose chemotherapy and total body irradiation for bone marrow transplant ⁹ Acceptable reliability ($r = 0.70$ – 0.86) Good construct validity ($r = 0.80$)	No studies identified	Observer report of subjective symptom but may be useful in situations when patients not able to comply with self-report	Behavioural phenomena may not be an accurate measure of subjective sensations

Appendix 2

Table A2 Global tools that may be considered for the assessment of emesis in a palliative care population

Instrument	Description	Administration	Symptoms	Evidence	Pros	Cons
Adapted symptom distress scale (Adapted SDS-2) Rhodes <i>et al.</i> ²⁷	31 items five-point Likert scale Assesses 14 symptoms Total score reflects symptom burden (occurrence and distress) Has a gastrointestinal subscale score Been used with oncology patients during treatment	Self-report Completion time 5 minutes	Nausea Vomiting	Patients assessed face validity Symptom prevalence literature used for content validity Construct validity assessed by comparing groups of well individuals with those with cancer Good test-retest reliability ($r = 0.92$) Good internal consistency (Cronbach's $\alpha = 0.76-0.91$)	Good psychometric properties Highest agreement for symptom occurrence and distress between nurses and patients for nausea and vomiting (although only weak to moderate agreement)	Not been specifically validated for use in palliative care population
Assessment of quality of life at end of life (AQEL) Axelsson <i>et al.</i> ⁵⁸	19 items modified linear 'analogue' scale with line divided into equally spaced integers 1–10. End points described verbally Developed for palliative care patients	Self-report Time to complete not stated	Nausea	Construct validity assessed using Karnofsky performance status (better QOL correlated with better performance status) Criterion validity (concurrent) assessed using Cancer Inventory of Problem Situations – mean correlation $r = 0.67$ Good test-retest reliability (mean correlation $r = 0.74$)	Practical Used with patients and spouses in palliative care ⁵⁸	No domain scores – harder to interpret
Edmonton Symptom Assessment Scale (ESAS) Bruera <i>et al.</i> ³⁹	9 items –each 10 cm VAS relating to a specific symptom (space for optional 10th symptom) Lower scores represent better symptom control Developed for palliative care patients	Self-report Completion time 5 minutes	Nausea Vomiting or retch could be added.	Construct validity assessed using Karnofsky performance status Criterion validity (concurrent) assessed using MSAS and FACT (moderate correlation for nausea $r = 0.62$) Small sample for test-retest reliability – strong correlation at 2 days ($r = 0.86$)	Useful in cancer patient population Can be useful audit tool for palliative care patients ⁵⁹	Differing opinions regarding use in palliative care population – many patients had difficulty with understanding and completing scale For patients nearing the end-of-life, ESAS not effective means of assessing symptom control ³⁶

Appendix 2

Table A2 (Continued)

Instrument	Description	Administration	Symptoms	Evidence	Pros	Cons
				and moderate at 7 days ($r = 0.45$)		
				Good internal consistency (Cronbach's $\alpha = 0.97$)		
EORTC QLQ-C30	30 items in total (9 multi-item Likert scales and single item questions)	Self-report	Nausea vomiting	Construct validity assessed using correlations with multi-item subscales, performance and disease status and treatment stage	Easy for oncology patients to understand and complete	In palliative care population, good internal consistency for overall QOL ($r = 0.83$) but lower for certain subscales
Aaronson <i>et al.</i> ²⁸	Assess QOL for specific cancers in clinical trials	Completion time 8–18.5 minutes		Convergent validity acceptable ($r > 0.40$) in 7/9 multi-item scales	Available in different languages ²⁸	Many palliative care patients need help. Cognitive impairment may affect acceptability of instrument and results ³³
	Been used with palliative care patients ³³			Moderate to good internal consistency (Cronbach's $\alpha = 0.52$ – 0.89) ²⁸	Palliative care module in development	
				Good test–retest reliability (range $r = 0.63$ – 0.91) but lowest for nausea and vomiting Hjerstad <i>et al.</i> ⁶⁰		
Functional assessment of cancer therapy–general scale (FACT–G)	28 items five-point Likert scale	Self-report	Nausea	Patients and oncology specialists generated items (providing evidence for face and content validity)	Easy to complete	Not tested in advanced cancer
Cella and Perry ³⁸	Used with oncology patients	Completion time 5 minutes		Construct validity (convergent and discriminant) assessed using FLIC, ECOG and other scales assessing mood and performance status	Sensitive to performance status, extent of disease	
				Good test–retest reliability ($r = 0.82$ – 0.92)	Sensitive to clinical change over time	
				Good internal consistency (overall Cronbach's $\alpha = 0.89$)		

Appendix 2

Table A2 (Continued)

Instrument	Description	Administration	Symptoms	Evidence	Pros	Cons
				Factor analysis also used to assess internal consistency and create five subscales		
Functional living index-cancer (FLIC)	22 items seven-point Likert scale	Self-report Completion time <10 minutes	Nausea	Construct validity assessed by factor analysis through three separate trials	Easy to use, administer and score ¹⁴	Not tested in palliative care population
Schipper <i>et al.</i> ⁶¹	Proposed as an adjunct to clinical trials			Concurrent validation studies against Karnofsky, Beck Depression, Katz Activities of daily living score and others		Performance in detecting changes over time has yet to be assessed
Revised Hospice Quality of Life Index (revised HQLI)	28 items 11 point rating scale	Self-report Completion time 10–15 minutes	Nausea	Literature review, patients and professionals used in development (providing evidence for face and content validity)	QOL measure sensitive to clinical change over time Adapted for use with terminally ill patients in other healthcare settings	Only been used with cancer patients Test-retest reliability not undertaken Weighting system complicated
McMillan <i>et al.</i> ¹⁹	Developed for palliative care patients – hospice home care setting in USA			Construct validity assessed using ECOG scores and factor analysis (demonstrated three subscales) Good internal consistency (Cronbach's $\alpha = 0.88$)		
Suffering in terminal illness (STIL)	43 items - five-point verbal rating scale	Self-report or interviewer-administered	Nausea vomiting	Healthcare professionals, one patient and two relatives involved in development (providing evidence for face and content validity)	95% patients with advanced cancer found assessment relevant (McAdam ²⁰)	Different response category for each question as well as negative phrasing – difficult to fill in
MacAdam and Smith ²⁰	Developed for palliative care patients with advanced cancer	Completion time 30 minutes		Factor analysis used to assess construct validity Criterion validity (concurrent) assessed for some symptoms		Test-retest reliability assessed 3–5 weeks later Lengthy to complete (3 pages).
McCorkle Symptom Distress Score (SDS)	13 items five-point Likert scale	Self-report Completion time 5–10 minutes	Nausea	High reliability and validity in cancer patients		Measures degrees of distress. Does not distinguish between

Appendix 2

Table A2 (Continued)

Instrument	Description	Administration	Symptoms	Evidence	Pros	Cons
McCorkle and Young ⁴³	Been used with oncology patients			Cronbach α = 0.78 and 0.79 for repeated administration		symptom occurrence and distress
Symptom Experience Scale (SES)	Developed from SDS	Self-report Mailed questionnaire	Nausea	Content validity assessed by psychoncology research fellows		Needs further validation in wider population including palliative care patients
Samarel <i>et al.</i> ²⁴	8 items five-point Likert scale Descriptive words operationalize each point on the scale Used with breast cancer patients on treatment	Completion time <10 minutes		Construct validity assessed using factor analysis (yielded 6 factors) Good internal consistency Overall Cronbachs α = 0.94		
Memorial symptom assessment scale (MSAS)	Multi-dimensional Ordinal Verbal rating scale and Likert. 33 symptoms and 3 dimensions (severity, distress and frequency) two subgroups – PSYCH and PHYS	Self-report Cancer patients Time to complete not stated	Nausea vomiting	Moderate to good internal consistency (Cronbach α = 0.88 and 0.83) Factor analysis used to assess construct validity Correlation findings suggest distress measure single most informative dimension	10 item global distress index – useful easy to interpret and can be used alone Provides quantitative info about global symptom distress and the impact of symptoms on various aspects of quality of life. PHYS subscale can be supplemented by detailed description of severity, frequency or distress of individual symptoms – useful for trials of treatments Distress scale yields most info about relationship between symptom and quality of life	Unable to delineate the occurrence and distress of the specific symptom eg, vomiting, limiting usefulness in assessing, planning and implementing appropriate interventions to manage specific symptoms
Portenoy <i>et al.</i> ²⁶						
McMaster (MQLS) ²³	32 items rated on a seven-point numerical scale Four dimensions identified: Physical, Emotional, Social and	24 hours recall Completion times: – Observer 3 minutes – Patients 3–30 minutes	Nausea vomiting	Good intra-rater reliability (r = 0.84) and internal consistency (Cronbachs α = 0.80)	Able to separately monitor physical and non-physical aspects of QOL sensitive to changes in patients condition	

Appendix 2

Table A2 (Continued)

Instrument	Description	Administration	Symptoms	Evidence	Pros	Cons
	Spiritual				The word form MQOL-W may be useful for confused patients but needs more testing	
	Palliative care patents					
Palliative care assessment tool (PACA) Ellershaw ²¹	Three domains Within symptom domain, severity of eight symptoms assessed using four-point verbal categorical rating scale Developed for hospital palliative care patients with cancer	Healthcare professional asks patient and completes form Time to complete not stated	Nausea Vomiting	Moderate to good inter-observer reliability ($\alpha = 0.48$ for nausea, $\alpha = 1.00$ for vomiting) Good criterion (concurrent) validity for nausea – used McCorkle symptom distress scale	Developed to measure efficacy at improving symptom control Concise and easy to use	Only been used in hospital setting
Quality of life index (QLI) Padilla ²⁵	10 cm linear analogue scale	Self-report Completion time <5 minutes	Nausea vomiting	Factor analysis used to provide evidence of construct validity of four subscales representing the four HQOL dimensions ie, Psychological, Physical, Symptoms and Nutrition ²⁵	Short completion time	Used mainly for fitter cancer patients. Not validated in palliative care patients
Resident assessment instrument for palliative care (RAI-PC) Steel <i>et al.</i> ²²	Needs assessment form for palliative care use Verbal rating score –whether N&V present and if distressing	Completed by healthcare professional – uses information from patient and family 20 minutes to complete by healthcare professional	Nausea and vomiting combined	Good inter-observer reliability for N&V ($\alpha = 0.82$)	Global assessment of needs Can be used to assess clinical change over time	Basic assessment of symptoms – more information may be required Limited psychometric testing Not available for patient completion
Rotterdam symptom checklist revised (RSCL) Watson <i>et al.</i> ³⁰ Developed from original RSCL	26 questions four-point Likert scale Time frame 'Over the last week' Developed for cancer patients with early stage disease undergoing chemotherapy Used in palliative care patients ³⁷ and anti-emetic trials in oncology (Bosnjak <i>et al.</i> ⁶²)	Self-report <10 minutes to complete	Nausea Vomiting	Factor analysis used to identify 1 psychological four physical subscales Good internal consistency Psychological subscale $\alpha = 0.86$ Overall physical subscales $\alpha = 0.77$ Validity of psychological subscale confirmed against HADS	Symptom orientated Revised version most useful for cancer patients	Difficult for palliative care patients to complete ³⁷ Not specifically measuring QOL in those with advanced disease (Hardy <i>et al.</i> ³⁷) No test-retest reliability data Used psychological tests to validate although majority of symptoms were physical ²⁹

Appendix 2

Table A2 (Continued)

Instrument	Description	Administration	Symptoms	Evidence	Pros	Cons
Modified Rotterdam Symptom Check list (RSCL-M)	28 question, Likert scale	Self-report Completion time not stated	Nausea vomiting	Convergent and discriminant validity measured	Wide range physical symptoms	Test-retest reliability not examined
Stein <i>et al.</i> ²⁹	Psychological dimension removed from RSCL revised New physical symptoms added Cancer pts			Good internal consistency (Cronbachs $\alpha = 0.88$) Sensitive to detect differences in physical distress between groups	Easy to complete	Needs further validation in heterogeneous populations

Appendix 3

Table A3 Assessment tools rejected following assessment

Rejected Tool	Reason rejected
Cancer Rehabilitation Evaluation System (CARES)	Tool for patients undergoing rehabilitation
The Fact Hepatobiliary Symptom Index (FHSI)	Specific to hepato-biliary cancer patients only
Morrow Assessment of Nausea and Emesis (MANE)	Designed specifically for use in anti-emetic studies of chemotherapy-induced nausea and emesis
Missoula Vitas QLI	Not specific enough for assessment of emesis
McGill QOL questionnaire (MQOL)	Does not ask specifically about nausea and vomiting
Patient evaluated problem score (PEPS)	Does not ask specifically about nausea and vomiting
Patient Outcome Scale (POS)	Does not ask specifically about nausea and vomiting
STAS	Does not ask specifically about nausea and vomiting
Schedule for the Evaluation of Individual Quality of Life (SEIQOL)	Does not ask specifically about nausea and vomiting
QL-Index (Spitzer)	Does not ask specifically about nausea and vomiting