

# Measuring health-related quality of life in cancer patients

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## Summary

The measurement of health-related quality of life (HRQoL) is being increasingly advocated in healthcare practice, particularly in relation to cancer care. The use of patient-reported health instruments has been recommended in Lord Darzi's review of the NHS. Consequently, nurses have to be aware of the most reliable and valid QoL measurement tools for given situations and conditions. The aim of this article is to review the most common HRQoL tools for use in the oncology setting, highlighting the specific properties of each instrument.

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## Keywords

**Cancer; Health and quality of life; Patient assessment; Psychology**

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THE NEEDS OF cancer patients can be assessed easily and accurately using patient-reported health instruments (PHIs). Previously such tools were used purely for clinical research, but their role in clinical assessment and diagnosis has now been recognised (Department of Health (DH) 2008a). *The Standard NHS Contracts for Acute Hospital, Mental Health, Community and Ambulance Services and Supporting Guidance 2008* (DH 2008b) includes a requirement under section 5 for health providers to report on evidence from PHIs from April 2009. Data collected using PHIs are to be collected by providers pre-operatively and submitted to commissioners (DH 2008c). There are a variety of generic, condition-specific and dimension-specific instruments available. The selection of instruments is a complex

process. It is important to take into consideration their psychometric and practical properties. Nurses can enhance patients' quality of care by using PHIs. An understanding of the underlying philosophy of these tools and how they can be used in cancer care are important aspects of oncological nursing theory and practice.

## Background

In England 242,200 new cases of malignant cancer (excluding non-melanoma skin cancer, were registered in 2006. Of these, 121,600 were in males and 120,600 in females (Office for National Statistics (ONS) 2008). Breast, lung, colorectal and prostate cancer accounted for more than half of these cases (ONS 2008). Increased survival rates due to earlier detection of screening procedures have resulted in cancer becoming a chronic disease for a large proportion of patients (Cardy 2005). Health-related quality of life (HRQoL) has therefore become an important consideration in the cancer journey (Cancer Research UK 2007). It is now recognised that HRQoL outcomes are just as important as 'hard' outcomes such as mortality (Rosenbaum *et al* 2006).

HRQoL is defined as 'a broad ranging concept incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment' (World Health Organization (WHO) 1998). It is one of the most important factors to measure as an outcome in patients with cancer. It is a multidimensional concept, encompassing all the domains that are of importance to the individual, including physical ability, psychological wellbeing and social life. Clinical research examining the role played by psychosocial variables in the cancer experience has traditionally measured HRQoL as an endpoint and not a factor to be monitored throughout the diagnosis, treatment and terminal or remission process (Waalens 1990,

Gotay *et al* 1992). Furthermore, measures of HRQoL in clinical settings typically require patients to rate their overall perceived HRQoL rather than distinguishing between the multidimensional nature of this concept in terms of physical, psychological and social wellbeing.

Measuring HRQoL using PHIs can be a useful process for oncology nurses or those carrying out research with cancer patients. In practice PHIs can help improve patient care by highlighting care needs, such as emotional and spiritual wellbeing, that would otherwise remain unknown. In research they can provide insight into subjective as opposed to objective outcomes. Bredin *et al*'s (1999) study shows how these instruments can be used in practice and research. Patients diagnosed with lung cancer ( $n=116$ ) were provided with a range of strategies, such as combining breathing control, activity pacing, relaxation techniques and psychosocial support. They completed various self-assessment questionnaires. These PHIs revealed significant improvements in breathing control, WHO performance status (WHO 1979), levels of depression, physical symptom distress and breathlessness. In this instance, PHIs were used in research that could then inform practice. Further examples of such applications will be illustrated for specific, frequently used, cancer instruments.

There are many instruments available for assessing HRQoL, from generic (measuring multiple concepts relevant to a wide range of patients) to specific (a disease, population or health dimension (Table 1)). They can be either patient-reported or clinician-reported instruments. Unless the patient is unable to complete the instrument, it is difficult to argue against patient-reported instruments being the most valuable in terms of capturing the patient experience. PHIs can enable patients to communicate their personal values, priorities, needs and expectations effectively in the context of their illness.

This article aims to identify the most common HRQoL PHIs used in oncology. The psychometric and practical properties of these instruments are discussed. Fitzpatrick *et al* (1998) have developed selection criteria for assessing the quality of PHIs (Table 2). These criteria will be referred to in this review.

## Method

The patient-reported bibliography *Patient-Reported Outcome Measures*, hosted by the National Centre for Health Outcomes Development at the University of Oxford, was

**TABLE 1**

Quality of life dimensions	
Dimension	Example
Physical function	Mobility, dexterity, activities of living.
Symptoms	Pain, nausea, energy levels.
<b>Perceived health</b>	
Psychological wellbeing	Anxiety, depression, coping, adjustment.
Social wellbeing	Family and intimate relationships, social contact, leisure.
Cognitive functioning	Alertness, concentration, memory.
Role activities	Employment, household management, financial concerns.
Personal constructs	Life satisfaction, spirituality, satisfaction with appearance.
Satisfaction with care	Speed of care, approachable staff, information provision.
Fitzpatrick <i>et al</i> (1998)	

**TABLE 2**

Questionnaire selection criteria	
Selection criteria	Example
Reliability	Is the questionnaire accurate over time?
Internal consistency	The extent to which individual items in a questionnaire scale measure the same construct, for example, homogeneity of items in the scale.
Test-retest reliability	The stability of the questionnaire over time. This is assessed by administering the instrument to respondents on two different occasions and examining the correlation between test and retest scores.
Validity	Does the questionnaire measure what is intended in different settings?
Responsiveness	Can the questionnaire detect clinically important changes over time, when changes are present?
Precision	Can the questionnaire distinguish between respondents in terms of health or illness?
Acceptability	Are patients willing to complete the questionnaire?
Feasibility	Is the timing and cost of questionnaire administration and scoring reasonable?
(Fitzpatrick <i>et al</i> 1998)	

searched for outcome measures used in oncology (<http://phi.uhce.ox.ac.uk>). The website includes a bibliography of more than 14,000 records of published instrument evaluations found on a number of electronic databases, such as the British Nursing Index, EMBASE, Medline and PsycINFO®. The database was searched using the key term 'cancer' which generated 272 records. The inclusion criteria for records were that the

population included in the research were adult cancer patients and that the properties of the instruments used were evaluated, which left 68 records for this review. The instruments discussed in this review elicited the greatest supporting evidence in terms of utility in the clinical environment.

## Results

The identified HRQoL PHIs have been categorised into those that are condition-specific measuring generic HRQoL and those that are dimension-specific measuring various aspects of psychological wellbeing.

**Condition-specific instruments** The most commonly used HRQoL instruments in oncology tend to have a generic and cancer-specific component, as is the case with the following three questionnaires.

**European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (Aaronson et al 1993)** The 30-item EORTC QLQ-C30, developed by the European Organization for Research and Treatment of Cancer Group, is a generic instrument developed to assess QoL in cancer patients. Nurses can use the questionnaire to assess changes in HRQoL throughout the cancer pathway and during or after a specific treatment regimen. There is therefore ample opportunity to identify negative disease or treatment side effects promptly (Bjoridal et al 2000, Greimel et al 2002). The domains measured include role functioning and physical, psychological and

social wellbeing. The tool is supplemented with disease-specific modules, for example breast, lung, head and neck, ovarian, gastric and cervical cancer, as well as multiple myeloma. Example items from each of the instrument domains are shown in Table 3. Answers are provided on a scale of 1 = not at all, 2 = a little, 3 = quite a bit and 4 = very much.

Some studies have found the reliability of the role functioning scale to be inadequate and have questioned whether it accurately measures the concept of role functioning. This was the case in a cohort of patients with non-resectable lung cancer (Aaronson et al 1993) and Dutch and Canadian patients with cancer (Osoba et al 1997). However, other studies have found the questionnaire reliable, valid and sensitive to change in various patient groups (Osoba et al 1998, McLachlan et al 1999). Extensive use of the EORTC QLQ-C30 has demonstrated that it is valid in different countries (Apolone et al 1998, Arraras et al 2002) and among long-term survivors (Apolone et al 1998) and palliative care patients (Kaasa et al 1995). The instrument has demonstrated responsiveness to the effects of chemotherapy (Osoba et al 1994), as well as palliative radiotherapy (Kaasa et al 1995). Scales and items in the instrument have demonstrated discriminative validity with different types and stages of cancer (Arraras et al 2002). The EORTC QLQ-C30 has been found to take less than 15 minutes to complete (Brédart et al 2005) and has demonstrated high completion rates in those with good performance status (Kobayashi et al 1998) as well as those with advanced cancer (Kaasa et al 1995). The instrument is flexible in terms of time and cost and can be self-administered or undertaken during an interview.

**Functional Assessment of Cancer Therapy – General (FACT-G) (Cella et al 1993)** The 27-item FACT-G measures multidimensional QoL, covering physical, social, emotional and functional wellbeing. It is appropriate for use with patients with any form of cancer. Nurses might find it useful in identifying symptom clusters (Paice 2004, Gleason et al 2007). As with the EORTC QLQ-C30, there are several scales that can be added to the FACT-G to measure disease and treatment-specific components of the cancer experience. Example items are shown in Table 4. Answers are provided on a scale of strongly agree, agree, unsure, disagree and strongly disagree.

Reliability has been confirmed in a number of studies (Cella et al 1993, Dapuelto et al 2003, Webster et al 2003, Lee et al 2004, Davies et al 2008). The instrument has been validated for use with special populations, such as older people (Overcash et al 2001), those living in

TABLE 3

### Example items from the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire

Domain	During the past week
Physical wellbeing	Did pain interfere with your daily activities?
Psychological wellbeing	Did you feel tense?
Social wellbeing	Has your physical condition or medical treatment interfered with your family life?
Role functioning	Do you need help with eating, dressing, washing yourself or using the toilet?
Breast cancer specific	Was the area of your affected breast swollen?
Lung cancer specific	Have you had trouble swallowing?
Ovarian cancer specific	Did you have abdominal pain?

(Aaronson et al 1993)

rural areas (Winstead-Fry and Schultz 1997), and among different cultures (Dapueto *et al* 2003, Lee *et al* 2004). The FACT-G has been found to be responsive to change in functional status over time (Webster *et al* 2003) and for this reason is often used in clinical trials (Cella *et al* 1993). The instrument is appropriate for use in the general population and for a variety of health conditions and different types of cancer and cancer treatments (Brucker *et al* 2005).

It has been found to discriminate between people receiving cancer treatment and those who are not (Overcash *et al* 2001). The instrument and its subscales are specific enough to capture clinically relevant problems associated with a condition or symptoms and are general enough to allow for comparison between diseases. Respondent burden is minimal since the questionnaire is written at the reading level of a nine year old and the average completion time is five to ten minutes (Cella *et al* 1993). The administrative burden is minimal, especially if self-administered as opposed to interview based. Computerised scoring programmes are available to aid the interpretation of patient scores.

**Quality of Life in Adult Cancer Survivors (QLACS) (Avis *et al* 2005)** The QLACS is one of the few instruments that explores the longer-term effect of cancer, with its focus on survivorship as opposed to illness. Nurses might find this a useful measure for assessing HRQoL among long-term cancer survivors who are not captured by generic measures (Avis *et al* 2006). The questionnaire consists of 47 items divided into seven generic QoL domains (negative feelings, positive feelings, cognitive problems, sexual problems, physical pain, fatigue and social avoidance) and five cancer-specific domains (appearance concerns, financial problems, distress over recurrence, family-related distress and benefits of cancer). Examples of items from each of these domains are shown in Table 5. For each item respondents answer on a scale of 1=never, 2=seldom, 3=sometimes, 4=about as often as not, 5=frequently, 6=very often and 7=always.

The instrument's reliability and validity have been confirmed (Carver *et al* 2005, Avis *et al* 2006). In a methodological review of cancer QoL instruments, the QLACS was the only one to demonstrate test/retest reliability (Pearce *et al* 2008). The questionnaire is responsive to long-term follow up of patients (Avis *et al* 2005) as well as life change (Avis *et al* 2006). The instrument has shown precision in comparisons between cancer and non-cancer populations, and has the ability to distinguish between respondents in terms of health or illness (Avis *et al* 2005). Few data are available on the

**TABLE 4**

**Examples of items in the Functional Assessment of Cancer Therapy - General instrument**

Domain	During the past seven days...
Physical wellbeing	I have lack of energy.
Emotional wellbeing	I am satisfied with how I am coping with my illness.
Social wellbeing	I feel close to my friends.
Functional wellbeing	I am able to work.
Breast cancer specific	I am self-conscious about the way I dress.
Prostate cancer specific	I am able to feel like a man.
Brain cancer specific	I am afraid of having a seizure (convulsion).
(Cella <i>et al</i> 1993)	

**TABLE 5**

**Examples of items in the Quality of Life in Adult Cancer Survivors instrument**

Domain	In the past four weeks...
Negative feelings	You felt blue or depressed.
Positive feelings	You felt happy.
Cognitive problems	You had difficulty doing activities that require concentration.
Sexual problems	You lacked interest in sex.
Physical pain	You had aches or pains.
Fatigue	You had the energy to do the things you wanted to do.
Social avoidance	You were reluctant to start new relationships.
Appearance concerns	You felt unattractive because of your cancer or its treatment.
Financial problems	You had problems with insurance because of cancer.
Distress over recurrence	You worried about cancer coming back.
Family-related distress	You worried that your family members were at risk of getting cancer.
Benefits of cancer	You appreciated life more because of having cancer.
(Avis <i>et al</i> 2005)	

acceptability of the instrument. However, a response rate of 78% has been reported by the developers (Avis *et al* 2006), which is consistent with response rates generally reported in follow-up studies of cancer survivors (Bloom *et al* 2004, Carver *et al* 2005).

**Dimension-specific instruments** If nurses are more interested in, or concerned about, a specific dimension (Table 1) of patient wellbeing, then there are a number of useful, dimension-specific PHIs available. The area that is now commonly being recognised as

important in patients with cancer is that of psychological wellbeing. Depression has been found to add significantly to the burden of chronic illness (Osborne *et al* 2004). Furthermore, physical improvements from cancer treatments can be observed where psychological symptomatology is appropriately treated (Hopwood *et al* 1991, Hopper *et al* 1994). The following two PHIs explore different aspects of psychological wellbeing. **The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983)** The HADS is an internationally accepted instrument for rating psychological morbidity in patients with cancer (Montazeri *et al* 2003). Nurses might use the HADS as a screening tool for patients about whom staff are concerned as it can identify the need to refer the patient for psychological or psychiatric assessment (Nordin *et al* 2001, Katz *et al* 2004). It comprises 14 items (seven for anxiety and seven for depression). Each subscale is designed to assess affective states independent of physical symptoms. Examples of subscale items can be seen in Table 6. Answer options vary

**TABLE 6**

Examples of items in the Hospital Anxiety and Depression Scale	
Domain	During the past week...
Anxiety	Worrying thoughts go through my mind. I can sit at ease and feel relaxed.
Depression	I can laugh and see the funny side of things. I feel as if I am slowed down.
(Zigmond and Snaith 1983)	

**TABLE 7**

**Examples of items in the Mental Adjustment to Cancer Scale**

Domain	During the past week...
Fighting spirit	I believe that my positive attitude will benefit my health.
Helpless/hopeless	I feel that there is nothing I can do to help myself.
Anxious preoccupation	I worry about the cancer returning or getting worse.
Fatalism	I feel fatalistic about it.
Denial (avoidance)	I avoid finding out more about it.
(Watson <i>et al</i> 1988)	

for each item but are along the lines of 'not at all', 'sometimes' and 'very often'. Each subscale is scored from 0 to 21: 0-7 indicates no clinical anxiety or depression, 8-10 indicates borderline clinical anxiety or depression, and 11-21 indicates clinical anxiety or depression (Zigmond and Snaith 1983).

The scale has been demonstrated to be succinct, acceptable to respondents and reasonably concordant with clinical ratings. It has also distinguished consistently between the two subscales of anxiety and depression across studies (Herrmann 1997). With a few exceptions, the HADS has demonstrated satisfactory reliability for the entire scale and for the anxiety and depression subscales (Moorey *et al* 1991, Leung *et al* 1993, Herrmann *et al* 1995). Retest reliability is good (Michopoulos *et al* 2008). The validity of the HADS has been shown in that its ability to detect clinical anxiety and depression is similar to that reported for other scales (Wilkinson and Barczak 1988, Meakin 1992, Ibbotson *et al* 1994). The instrument has demonstrated responsiveness to psychopharmacological interventions, such as antidepressants and psychosocial interventions (Herrmann 1997). The anxiety and depression subscales have been found to discriminate between groups of patients differing in tumour severity (Montazeri *et al* 2003). A review of more than 200 studies using the HADS found that a large number of the studies reported 100% response rates (Herrmann 1997), indicating extremely high patient acceptability. The scale can be completed in two to six minutes and scored in one minute, making it ideal for hospital environments (Herrmann 1997).

Despite the evidence supporting the use of the HADS in oncology, the instrument should be used with caution in patients coming to the end of the illness trajectory. Cancer progression often manifests with symptoms commonly associated with depression, such as fatigue, loss of appetite and reduced activity. Such symptoms are an inevitable consequence of terminal illness and are not necessarily indicative of depression. It is essential to consider such factors in interpreting responses to the HADS.

**Mental Adjustment to Cancer Scale (MACS) (Watson *et al* 1988)** The MACS is a 40-item questionnaire designed to assess specific ways of responding to cancer. The instrument is widely used to determine the extent to which patients have adjusted to living with cancer. Nurses might find it useful in assessing how well patients are coping with their diagnosis or treatment (Stanton *et al* 2000, Purushotham *et al* 2005). The scale has five subscales: fighting spirit; helpless/hopeless; anxious preoccupation;

fatalism; and denial (avoidance). Examples of items from each of these subscales are outlined in Table 7. Answers are provided on a scale of 'definitely does not apply to me', 'does not apply to me', 'does apply to me' and 'definitely does apply to me'.

Data on the reliability of the MACS have been mixed. In a study of 632 patients with breast cancer, the fighting spirit and helpless/hopeless subscales were high on reliability, but the other subscales were less satisfactory (Osborne *et al* 1999). The MACS has demonstrated validity when patient-reported outcomes are compared with spouse-reported outcomes (Watson *et al* 1988) and clinical outcomes (Greer *et al* 1989). The instrument is also valid cross-culturally (Watson *et al* 1988, Schwartz *et al* 1992, Ferrero *et al* 1994) and for palliative care patients (Mystakidou *et al* 2005). It has been found to correlate with instruments measuring

the same concept (Osborne *et al* 1999). The instrument demonstrates precision in its design, whereby mental adjustment and coping are measured as distinct concepts (Nordin *et al* 1999). Ease of use has been maintained through the development of the 29-item Mini-MAC, which has been found to be a useful tool for obtaining rapid, reliable and economical assessment of mental adjustment to cancer (Watson *et al* 1994). This is ideal for oncology settings.

## Discussion

This article has considered three reliable PHIs measuring generic and condition-specific QoL, and two that focus on psychological wellbeing. With psychometric and practical properties, the three recommended condition-specific QoL instruments are the EORTC QLQ-C30 (Aronson *et al* 1993), the

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FACT-G (Cella *et al* 1993), and the QLACS (Avis *et al* 2005).

If nurses are interested in the current symptoms and experiences of the patient with cancer, then the first two are more appropriate. The QLACS is an ideal instrument for measuring the long-term experiences of such patients. The two recommended dimension-specific instruments are the HADS (Zigmond and Snaith 1983) and the MACS (Watson *et al* 1988). The HADS is a reliable tool for identifying those patients with needs specific to the symptoms of anxiety and depression, which are frequently experienced by cancer patients. The MACS measures a similar health outcome, but in the form of adjustment to cancer. The HADS is

recommended over the MACS because of the extensive, evaluative studies confirming its reliability and validity, as well as its acceptability to patients and nursing practices (Herrmann 1997, Montazeri *et al* 2003). Used in combination with more commonly employed nursing research methods, which are qualitative and naturalistic, and nursing practice designed to improve patient care and satisfaction, these instruments can provide nurses with greater understanding of individual patient needs and can enhance patient care.

## Conclusion

This article is not comprehensive but does provide a thorough exploration of some of the most widely used HRQoL instruments in oncology. Nurses are advised to use the information alongside their own research to identify the most appropriate instrument for the

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**Nordin K, Berglund G, Glimelius B,**

desired outcome. It is advised that any subsequent reviews of potential health outcome instruments incorporate the selection criteria outlined in Table 1 (Fitzpatrick *et al* 1998).

It is important to assess the needs of patients with cancer in terms of their overall health and wellbeing and their psychological wellbeing. PHIs should be used more widely in nursing research and practice (DH 2008a). Many instruments are available, but not all are reliable and some might provide inaccurate assessments, acting as a burden to patients and nurses. Therefore it is necessary to understand the underlying philosophy behind these tools and be selective in choice. Nurses should think carefully about desired outcomes before administering the instrument so that they can make an informed decision about whether the chosen instrument is the most suitable for the patient, the nurse and the service being provided **NS**

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