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- UCQLQ-Kit Core questionnaire (4 pgs)
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- UCQLQ-Kit Verious Cancer Modules questionnaires ie. -
  - Bone Metastases
  - Breast
  - Colorectal
  - Elderly Cancer Patients
  - Endometrial
  - Head & Neck
  - Information
  - Neuroendocrine
  - Oesophago
  - Ovarian
  - Colorectal Liver Metastases
  - Cervical Cancer
  - Gastric
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Reliability and validity of the QLQ-C30 in palliative care cancer patients

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Abstract: Palliative care aims at improving the patient’s quality of life. The assessment of this quality of life (QoL) is crucial for the evaluation of palliative care outcome. Many patients require hospital admissions for symptom control during their cancer journey and most of them die in hospitals, although they would like to stay at home until the end of their lives. In 1986, the European Organization for Research and Treatment initiated a research programme to develop an integrated, modular approach for evaluating the quality of life of patients participating in international clinical trials. This questionnaire measures cancer patients’ physical, psychological and social functions and was used in a wide range of clinical cancer trials with large numbers of research groups and also in various other non-trial studies. The aim of this study was to evaluate the psychometric properties, especially the reliability, validity and applicability of the QLQ-C30 in a German sample of terminally ill cancer patients receiving palliative care in different settings. The questionnaire was well accepted in the present patient population. Scale reliability was good (pre-treatment 0.80) especially for the functional scale. The results support the reliability and validity of the QLQ-C30 (version 3.0) as a measure of the health-related quality of life in German cancer patients receiving palliative care treatment.

Keywords: QLQ C30 • Health-related quality of life • Palliative care • Cancer • Nursing research

1. Introduction

Palliative care is defined by the World Health Organization as an approach that improves the quality of life of patients and their families, whom face problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems. Palliative care:
• provides relief from pain and other distressing symptoms;
• affirms life and regards dying as a normal process;
• intends neither to hasten nor postpone death;
• integrates the psychological and spiritual aspects of patient care;
• offers a support system to help patients live as actively as possible until death;
• offers a support system to help the family cope during the patients’ illness and in their own bereavement;
• uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
• will enhance quality of life, and may also positively influence the course of illness;
is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. Therefore, there is a wide scope for research. In addition, there is also a need for research into the management and organisation of services and their quality of care. In recent years, attention on palliative care has a considerable increase in most European Countries in all areas of health care. As palliative care emerges it is becoming clear that it needs to take place in a wide range of settings, e.g., hospital, hospice, nursing home, day care and patients’ homes. In Germany the progression in this specialty is far behind the advancements, i.e., the UK. Currently, there is a reorganisation in the German health care system. There is the official political principle that home care is primary to hospital or nursing home care, thus, in the next few years, there will be a reduction in hospital beds by one-third, which will enforce a rapid change from hospital to home care. German politicians have yet to find a solution to transfer the high quality of palliative care from the established settings, i.e., hospice or palliative care units to the community environment. The new situation and the demand for more specialised palliative care teams increase the need for evaluation of the effect and quality of care.

Health-related quality of life assessment in cancer patients has attracted an increasing interest in recent years, particularly in the oncology nursing discipline. There it includes an assessment of the impact of the disease and its treatment on the physical, psychological and social functioning of the patient [2]. Many excellent validated self-completion questionnaires to measure HRQOL for patients with cancer are available, e.g., EORTC QLQ-C30, Functional Assessment of Cancer Therapy (FACT) (Holzner, Kemmler et al. 2004) [30], Rotterdam Symptom Checklist (RSCL) (Hardy, Edmonds et al. 1999) [28] and Functional Living Index-Cancer (FLIC) (Anunziata, Foladore et al. 1998; Kuenstner, Langelotz et al. 2002) [5, 40]. Other relevant instruments for palliative care include the Support Team Assessment Scale (STAS) (Carson, Fitch et al. 2000) [16], the McMaster Quality of Life Scale (MQLS) (Sterkenburg, King et al. 1996) [52] and the Symptom Distress Scale (SDS) (Heedman and Strang 2001) [29]. All those questionnaires are multidimensional, covering a minimum of the physical, psychological and social domains as well as some overall judgements of the validation of life or the health condition. It is hardly necessary (or advisable) to develop more or new instruments, but there should be clear recommendations and guidelines on which instruments are capturing the most relevant issues of concern for people with palliative care needs although there has been much criticism of the QLQ-C30 for use in palliative care by not covering important domains (e.g., spirituality).

In 1986, the European Organization for Research and Treatment of Cancer study group on quality of life initiated a research programme the long-term objective of which was to develop an integrated measure system for evaluating the HRQOL of patients participating in international clinical trials (Aaronson, Ahmedzai et al. 1993) [1]. Systematic evaluation of health-related quality of life (HRQoL) could enable clinicians to identify patients who are at an increased risk of encountering psychosocial problems, so that appropriate intervention strategies can be initiated where necessary (Bliss and While 2003) [13]. Sufficient validity and reliability are mandatory for any measuring tools (Kaasa, Bjordal et al. 1995; Klee, Groenvold et al. 1997; Sprangers, Cull et al. 1998) [33, 37, 50] especially for the use in palliative care with terminally ill patients.

The EORTC quality of life questionnaire is an integral system for assessing the HRQOL of cancer patients. A first-generation core questionnaire, the EORTC QLQ C36, was developed in 1987 by Aaronson and Beckmann (Beckmann, Betsholtz et al. 1988) [10]. The EORTC QLQ-C30 is a second-generation questionnaire. It is a 30-item questionnaire with a 4-point answer scale. Following its general release in 1993 (Aaronson, Ahmedzai et al. 1993) [1], the QLQ-C30 was used in a wide range of clinical cancer trials by a large number of research groups (Anderson, Aaronson et al. 1996; De Boer, Sprangers et al. 1996; Curran, Fossa et al. 1997; Curran, van Dongen et al. 1998; Kiebert, Curran et al. 1998; Langendijk, Aaronson et al. 2000; de Haes, Curran et al. 2003) [1, 4, 20, 21, 23, 35, 42, 50] and was additionally used in various other non-trial studies (Ahmedzai and Brooks 1997; Stromgren, Groenvold et al. 2001; Bestall, Ahmed et al. 2004) [2, 11, 54]. The EORTC QLQ-C30 has been designed for use in a range of languages and cultures, the validation of the QLQ-C30 specific to a German population and the development of disease-specific modules to supplement the EORTC QLQ-C30. Patients receiving palliative care treatment are usually in an end-stage situation on their illness, in this study cancer. At present, they have received curative treatments, which include chemotherapy, hormonotherapy, radiotherapy and surgery. But when the cancer deteriorates under these therapies and no other possibilities did help, the palliative care treatment increasingly became the centre of clinical possibilities.
Introduction

The quality of life questionnaire (QLQ) is an integrated system for assessing the health-related quality of life (QoL) of cancer patients participating in international clinical trials. The core questionnaire, the QLQ-C30, is the product of more than a decade of collaborative research. Following its general release in 1993, the QLQ-C30 has been used in a wide range of cancer clinical trials, by a large number of research groups; it has additionally been used in various other, non-trial studies.

This manual contains scoring procedures for the QLQ-C30 versions 1.0, (+3), 2.0 and 3.0; it also contains summary information about supplementary modules.

All publications relating to the QLQ should use the scoring procedures described in this manual.

This manual will be updated at regular intervals, to reflect future changes to the QLQ and to incorporate new supplementary modules.
**QLQ-C30** (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:

Your birthdate (Day, Month, Year):

Today's date (Day, Month, Year):

<table>
<thead>
<tr>
<th></th>
<th>Not at All</th>
<th>A Little</th>
<th>Quite a Bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Do you have any trouble taking a long walk?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Do you have any trouble taking a short walk outside of the house?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Do you need to stay in bed or a chair during the day?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Do you need help with eating, dressing, washing yourself or using the toilet?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**During the past week:**

<table>
<thead>
<tr>
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<th>Not at All</th>
<th>A Little</th>
<th>Quite a Bit</th>
<th>Very Much</th>
</tr>
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<tbody>
<tr>
<td>6. Were you limited in doing either your work or other daily activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Were you limited in pursuing your hobbies or other leisure time activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>8. Were you short of breath?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>9. Have you had pain?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. Did you need to rest?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>11. Have you had trouble sleeping?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>12. Have you felt weak?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>13. Have you lacked appetite?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>14. Have you felt nauseated?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. Have you vomited?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. Have you been constipated?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</tbody>
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Please go on to the next page.

This is the end of the sample UCQLQ-Kit core questionnaire. Return to page 1 to purchase complete version.