

## EORTC QLQ-15 PAL questionnaire as tool for determining the quality of life of patients with pancreas adenocarcinoma – preliminary study

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**A** – Study Design, **B** – Data Collection, **C** – Statistical Analysis, **D** – Data Interpretation, **E** – Manuscript Preparation, **F** – Literature Search, **G** – Funds Collection

**Summary Background.** In neoplastic diseases, quality of life often has to be balanced against duration of life, therefore adequate psychological support and optimal pain management are extremely important. The QLQ-C15 PAL questionnaire is recommended to be used for patients with advanced, incurable and symptomatic cancer, with an expected survival time of a few months, not undergoing anti-cancer treatment.

**Objectives.** The aim of the study was to define, using the QLQ-C15 PAL questionnaire, the quality of life related needs of a group of patients with pancreas adenocarcinoma and to evaluate the questionnaire's practical usefulness for palliative care monitoring and its ongoing improvement.

**Material and methods.** A Polish translation of the QLQ-C15 PAL questionnaire was used in the year 2010 to estimate the quality of life of 26 patients with advanced stage pancreas adenocarcinoma, subjected to palliative care outside hospitals in the Lower Silesia region of Poland.

**Results.** The majority of patients in the surveyed group considered their quality of life to be quite good, but the study pointed out 2 patients complaining of very poor quality of life, thus requiring a reevaluation of their needs and the strategy of their palliative support.

**Conclusions.** The QLQ-C15 PAL questionnaire is a rapid and effective means to find out both the needs of particular patients and the characteristics of palliative care-covered patients groups. Its use enabled quick identification of those patients needing care adjustment. In cases when the questionnaire is filled in repeatedly over a longer period of time by the same patients, it can be useful in tracing the effectiveness of palliative care as measured by the patient's quality of life.

**Key words:** palliative care, health-related quality of life, questionnaire study, pancreas adenocarcinoma.

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## Background

It is not unlikely for primary care physicians to have patients suffering from pancreatic tumors. Neoplasms are an important cause of both morbidity and mortality [1], and pancreas adenocarcinoma is one of the health problem of growing importance in developed countries, including Poland and its Lower Silesia region, because the cases of pancreatic tumors have been increasing in number over the recent decades [2]. The existence of a link between modern lifestyle and the incidence of increased pancreatic cancers was proven previously many years ago – especially in case of smoking tobacco [3]. Lifestyle elements can be modified, but to actually change people's everyday life habits is an extremely demanding task of public health activities [4]. The diagnosis of pancreatic cancer is often not easy to confirm, even in cases in which the existence of a tumor has already been clinically detected – there are many chronic diseases demonstrating pancreas distortion or changed pancre-

as tissue consistency, including chronic recurrent pancreatitis, which is the most common among them [5]. Nowadays, microscopic techniques are crucial elements allowing final confirmation of the diagnosis – although sometimes this is possible only after the patient's death, when specimens retrieved during an autopsy are available [6].

Pancreas adenocarcinoma is associated with a poor survival prognosis, because, typically, the diagnosis is established late. Among the most frequently reported symptoms are: asthenia, weight loss, anorexia, abdominal pain, epigastric pain, darkened urine, jaundice, nausea, back pain, diarrhea, vomiting and steatorrhea. The signs that are most commonly observed in such patients are: jaundice, hepatomegaly, right upper quadrant mass, cachexia and Courvoisier's sign [7]. Very often these symptoms and signs become apparent only in the advanced stage of the tumor's development, when the distant metastases are already present [5]. Even the most diligent family medicine doctors who perform regular checkups of the medical history and current



physical status of their patients often find themselves helpless, as many of the early symptoms are nonspecific, and they keep being associated with possibly insignificant causes other than cancer by both medical professionals and their patients [8].

In the case of neoplastic diseases, the quality of life often has to be balanced against duration of life – as a gain in the former is, in most cases, associated with a loss in the latter and vice-versa. Pancreatic tumors are well known to medical staff as often being associated with an extremely poor prognosis and short survival times after diagnosis, and thus it is crucial to both patients and physicians to seek an optimal balance between treatment aggressiveness, expected increase in lifespan and acceptable quality of life. It is highly important for terminally ill patients to receive adequate psychological support and to be subjected to optimal pain and other suffering treatment – in this way, it is possible to prevent patient suicide, which is not uncommon [9], and a demand for euthanasia, which is unacceptable [10]. Cases of both suicide and euthanasia are sometimes not easy to detect, especially in cases mimicking accidental overdose of medication [11].

A modern approach to psychological health maintenance involves surveying and supporting not only the patient, but also the patient's family members in order to facilitate a positive, task-oriented style of coping with stress [12]. Regular attempts at early determination of any factors negatively influencing a patient's quality of life allow one to prevent or at least slow down the deterioration of general physical health. Otherwise, a worsening in one's general health status causes, in turn, a further deterioration in quality of life, thus leading to a vicious circle. As a patient's nutritional status is often already impaired at the moment of cancer diagnosis, anemia and cachexia prevention are of vital importance [13], which is not an easy task, as cachexia mechanisms are complicated [14], and nutritional deficits vary significantly from case to case and evolve over time [15]. Very often, the resulting anemia needs to be treated [16]. A patient's satisfaction with oncologic and palliative therapy is directly correlated with the level of compliance and inversely correlated with demands for "alternative medicine" practices [17]. This makes the availability of proper tools designed for evaluating the quality of life of patients with pancreatic tumors a very important factor for both effective palliative care and the practice of primary care physicians.

## Objectives

The aim of the study was to define, using the QLQ-C15 PAL questionnaire, the quality of life related needs in the group of patients with pancreas adenocarcinoma and to evaluate the questionnaire's practical usefulness for palliative care monitoring and its ongoing improvement.

## Material and methods

A Polish translation of the QLQ-C15 PAL questionnaire was used in the year 2010 to estimate the quality of life of 26 patients suffering from advanced stage pancreas adenocarcinoma and who were subjected to inpatient palliative care in the Lower Silesia region of Poland. The QLQ-C15 PAL questionnaire consists of 15 closed, single-choice questions – the 4 available answers to each of them are coded by digits from 1 to 4, with the answers being: "Not at All", "A Little", "Quite a Bit" and "Very Much", respectively. The questions are as follows: "Do you have any trouble taking a short walk outside of the house? Do you need to stay in bed or in a chair during the day? Do you need help with eating, dressing, washing yourself or using the toilet? During the past week: Were you short of breath; Have you had pain; Have you had trouble sleeping; Have you felt weak; Have you lacked appetite; Have you felt nauseated; Have you been constipated; Were you tired; Did pain interfere with your daily

activities; Did you feel tense; Did you feel depressed?". Only the last question, "How would you rate your overall quality of life during the past week?" uses the scale from 1 to 7, coding the answers from "Very Poor" to "Excellent", respectively. Patients were qualified to take part in the study based on diagnosis of wide-spread pancreas adenocarcinoma confirmed by needle biopsy or microscopic examination and those qualifying for palliative care – no other criteria limiting the study group were used. Patients were assisted by medical staff familiar with the demands of the protocol when filling in the questionnaires and were thus able to be provided with any explanations needed. Data was collected into a spreadsheet and analyzed using Microsoft Excel 2007 software.

## Results

None of the study's 26 participants needed much help with basic everyday life activities, such as eating, dressing, washing or using the toilet; however 5 (20%) of them needed some help – 2 (8%) needed quite a bit help, 3 (12%) needed a little bit help, and 16 (60%) did not need help at all. In the surveyed group, there was 1 (4%) bed ridden patient, 4 (16%) patients that needed to stay in bed or in a chair during the day 'quite a bit', 18 (68%) of them needed to do this 'a bit', and 3 (12%) did not need it at all. Taking a short walk outside of the house troubled 3 (12%) of the respondents 'very much', 4 (17%) of them had 'quite a bit of problem' with it, 7 (25%) of them declared having 'a little bit of problem' with leaving the house, and 12 (46%) did not have such problems at all. Dyspnea was intense in the last week prior to examination in 1 (4%) of the patients, 3 (11%) of them declared that they were short of breath 'quite a bit' during the previous week, 7 (27%) of the patients complained of being 'a little bit' short of breath, and 15 (58%) of them did not complain of dyspnea at all. The question concerning the occurrence of pain over the previous week was answered negatively by 1 (4%) of the patients, 13 (50%) of them had 'a little pain', 10 (38%) patients suffered 'quite a bit of pain', and 2 (8%) of the patients complained of having 'very much pain' during the previous week. All patients had some sleeping problems: 13 (50%) reported having 'a little' trouble sleeping, 12 (46%) had 'quite a bit' of trouble, and 1 (4%) admitted having 'very much trouble' with sleep. The question if patients felt weak over the previous week was answered negatively by 2 (8%) of the patients, 12 (48%) complained of feeling 'a little' weak, 7 (28%) stated that they were feeling 'quite a bit' weak, and 4 (16%) felt weak 'very much' in the week prior to when the study was conducted. Among the surveyed patients, 11 (42%) had 'no problems' with appetite, 8 (31%) reported 'a little' lack of appetite, 5 (19%) lacked appetite 'quite a bit', and 2 (8%) had 'no' appetite. Nausea was absent in 12 (46%) of patients, 8 (31%) of them complained about a being 'a little' nauseated during the week before the study, 5 (19%) patients felt nausea 'quite a bit', and 1 (4%) reported being nauseated 'very much'. The question concerning constipation was answered negatively by 10 (40%) of the surveyed patients, another 10 (40%) of them felt 'a little bit' constipated during the previous week, 4 (16%) of the patients were constipated 'quite a bit', and 1 (4%) of the patients complained about being constipated 'very much'. None of the patients asked about being tired provided a negative answer – 19 (72%) of them reported being 'a little' tired during the previous week, 2 (8%) admitted being 'quite a bit' tired, and 5 (20%) complained about being tired 'very much'. No interference of pain with their daily activities during the previous week was reported by 2 (8%) of patients, while 16 (62%) of them admitted 'a little' such interference, 5 (19%) felt being subjected to such interference 'quite a bit', and in 3 (11%) of the patients, pain interfered with their daily activities 'very much'. A feeling of tension during the week prior to when the study was conducted was absent in 6 (23%) of patients, 14 (54%) of them complained about feeling 'a little' tense, 'quite a bit' of tension was reported by 5 (9%) of

the patients, and 1 (4%) felt tense 'very much'. Among the patients involved in the study, 7 (27%) were not feeling depressed during the previous week, 14 (54%) of them reported feeling 'a little' depressed, 3 (11%) complained about feeling 'quite a bit' depressed, and 2 (8%) felt depressed 'very much'. Using the scale from 1 point (very poor) to 7 points (excellent), most of the surveyed patients rated their overall quality of life during the previous week as 4 points – 10 (38%) patients – or 5 points – 9 (35%) patients; a rating of 6 points and 7 points was chosen by 1 (4%) patient each; and a rating of 1 and 3 points – by 2 (8%) and 3 (11%) of the patients, respectively. The 2 patients who reported pain limiting their life activities and mobility, nausea, constipation and intense feelings of tension or depression also considered their quality of life as very poor.

## Discussion

Many questionnaires have been developed over recent years for the purposes of estimating the quality of life of patients suffering from different kinds of illnesses. These questionnaires are the subject of ongoing evaluation efforts that aim at improving both consistency of form and accuracy of results. The QLQ-C15 PAL questionnaire is recommended to be used in patients with advanced, incurable and symptomatic cancer with expected survival times of a few months who are not subjected to anti-cancer treatment, including chemotherapy, radiotherapy, endocrine treatment or surgery. Since the QLQ-C15 PAL questionnaire is an abridged, and thus extremely concise, version of the classic QLQ-C30 PAL questionnaire, it only demands patients to provide answers to 15, instead of 30, questions that are assumed to be of core importance [18]. The QLQ-C15 PAL questionnaire has been successfully used to assess quality of life in palliative patients with lung, breast, colon and prostate cancer [19]. Accepting a previously developed and validated questionnaire is a reasonable strategy in everyday medical practice [20], as it is highly difficult to build such a tool independently [21], especially for the purposes of quality of life estimations [22] that need to be precisely adjusted for the purposes of well-defined target groups [23]. As the practical usefulness of a particular questionnaire can differ due to a wide variety of reasons, especially from country to country, it is also accepted to reassess the usefulness of questionnaires [24].

A pilot study was performed by applying the QLQ-C15 PAL questionnaire to a limited group of patients, and thus the study only preliminarily confirmed its practical usefulness in evaluat-

ing cases of pancreas adenocarcinoma. The questionnaire allowed one to determine each patient's particular needs, as well as the suffering profile of the entire examined group. The study revealed that most patients with pancreas adenocarcinoma supported by palliative care outside hospitals were highly independent in everyday activities at home, although some of them needed support to leave home – as most of them felt weak and tired. Pain and sleeping problems were present in most of the patients – the pain was not severe in most cases, but it did interfere with a vast majority of patients' everyday activities. This raises the question if the pain was sufficiently controlled prior to the study. Feelings of tension and depression were reported by most of the patients; however, in most cases, these feelings were not intense. Dyspnea, constipation, nausea and lack of appetite did not constitute any major problem in this group of patients, and thus it can be assumed they were sufficiently controlled by proper medication. Generally, the majority of patients in the surveyed group considered their quality of life to be quite good, but the results of the study pointed out 2 patients complaining of very poor quality of life, which need reevaluation of both the existing needs profile and the strategy of relevant palliative support.

## Conclusions

The QLQ-C15 PAL questionnaire used in the group of 26 patients in pancreas adenoma palliative care identified the most common problems for quality of life as being a dependency on others, experiencing mild depression, weakness and tiredness, pain interfering with everyday activities and sleeping problems. Its use enabled rapid identification of those patients needing adjustment to care. Based on the results of the study, the QLQ-C15 PAL questionnaire is a quick and effective means of determining both the needs of particular patients and the characteristics of entire groups of palliative care-covered patients. In cases when a questionnaire-based assessment is repeated regularly, it can be useful in tracing the effectiveness of palliative care as measured by patients' quality of life, thus providing palliative medicine specialists and family doctors a feedback-based chance to improve their services. It can also be used to adjust the range of palliative medical services based on the needs of both particular patients and groups of patients supported by a given medical team. The preliminary study will be continued on a larger group of patients to allow for a cross-comparison of the efficacy of different questionnaires concerning quality of life in the case of patients with pancreas cancer.

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